Bereavement and Individuals with Learning Disabilities: An Evaluation of the Impact of Staff Training on the Knowledge and Confidence of Support Staff

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DECLARATION

I declare that I am the sole author of this thesis and that the work contained herein is my own. This thesis, or any part of it, has not been submitted for any other degree or professional qualification

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ABSTRACT

OBJECTIVE

This study aimed to investigate whether staff training, for staff from support provider organisations, improved knowledge about bereavement and grief, in general and in relation to individuals with a learning disability, and of supporting an individual with a learning disability at a time of bereavement. In addition, the study also aimed to investigate whether training improved staff members self rated levels of confidence about offering support to an individual with a learning disability who has experienced bereavement.

METHOD

A mixed design was used to investigate the impact of a one day training course on the above factors. A total of forty eight participants were recruited for the study and were randomly assigned to one of two groups, each consisting of twenty four members of staff. In addition to the development of a one day training course, a questionnaire was designed for the purpose of assessing the study's hypotheses and was completed by participants prior to training, immediately after training and one month following completion of the training.

RESULTS

Staff training was shown to significantly improve knowledge overall and in all three areas measured. These knowledge gains were maintained one month following completion of the training course. Differences were also found in the number of response categories identified by participants before and after training, with a broader range of answers post-training. Training also significantly improved participants' self rated levels of confidence about supporting an individual with a learning disability who has experienced bereavement. In addition to this, the validity and reliability of the questionnaire was analysed, with results confirming the questionnaire to be a reliable and valid measure.

DISCUSSION

A one day training course significantly improved staffs' knowledge about bereavement and grief, in general and in relation to individuals with a learning disability, and of supporting an individual with a learning disability at a time of bereavement. Training also significantly improved staffs' self rated levels of confidence about supporting an individual with a learning disability who has experienced bereavement. The clinical and ethical implications of the study are discussed along with limitations and suggestions for further research outlined.

CHAPTER 1: INTRODUCTION

Over the past three decades, bereavement and grief have received increasing attention in the literature with significant contributions being made to the research and evidence base. The field of bereavement and grief, however, still remains a relatively young area of research (Stroebe, Hansson et al., 2007). This is quite astounding given that death is a universal and inevitable part of the human experience, which can have extensive consequences for the bereaved individual (Raphael, 1984; Stroebe et al., 1993). Death has been described as a taboo subject that individuals would prefer to ignore or avoid (Conboy-Hill, 1992; Kloeppel & Hollins, 1989), which could possibly explain the lack of attention the topic has received. Increased interest in this area has, however, led researchers to develop theories of normal and complicated grieving, models to explain the grieving process and the identification of risk factors for bereavement outcome.

Despite these advances, one area that has received much less attention is bereavement and grief in individuals with learning disabilities. In the past it was assumed that individuals with learning disabilities were incapable of progressing through the grieving process in a similar manner to that of the general population (McLoughlin, 1986). Researchers have since challenged this notion and the ability of those with learning disabilities to grieve has gradually been acknowledged, as has the requirement to address their needs in a sensitive and supportive manner (Oswin, 1991). It has also been recognised that some individuals with learning disabilities may require additional support at a time of bereavement, highlighting the importance

of the role of families and staff at these times (Cathcart, 1995; Read & Elliott, 2003). It is, therefore, imperative that those individuals providing support have adequate information and skills to ensure the needs of the bereaved individual are met. Researchers have highlighted the need for staff training to ensure those supporting individuals with a learning disability have sufficient knowledge and understanding of the grieving process, in order to provide effective and appropriate support at these times (Cochrane, 1995; Kitching, 1987; Oswin, 1985).

The purpose of the current thesis was to design a training course focusing on bereavement and learning disability. This training would be offered to staff working within support provider agencies for adults with learning disabilities in the researcher's Health Board Area. Their knowledge and understanding of bereavement related issues was assessed before and after to determine any benefits from receiving the training course, specifically with regards to any increase in knowledge and also confidence about offering support to an individual with a learning disability at a time of bereavement. In order to introduce the study, bereavement and grief will firstly be discussed, with a general overview of theories, models, grief responses, risk factors for bereavement outcome and complicated grieving as applicable to the general population. Following this, bereavement and grief in individuals with learning disabilities will be explored, with discussion of potential complications and additional difficulties that may present for these individuals. A review of the literature on supporting an individual with a learning disability at a time of bereavement will be conducted. Finally, the role of staff training will be explored, before the aims and hypotheses of the study are outlined.

1.1 BEREAVEMENT AND GRIEF

Bereavement has been described as a loss that triggers the expression of grief, which is characterised by intense emotional distress (Lake, 1984; Simos, 1979; Stroebe et al., 1993). Another term commonly cited in the literature is that of mourning, which signifies the behaviours and actions associated with the expression of grief that are often shaped by cultural beliefs and religious practices (Stroebe et al., 1993). Grieving is a highly individualised and complex process that can have extensive consequences for the bereaved individual (Lake, 1984; Schuchter & Zisook, 1993). Despite the negative impact often associated with bereavement, the process can also be viewed as adaptive, in terms of promoting an individual's growth and resilience (Lake, 1984; Stroebe & Stroebe, 1993).

1.1.1 Theories of Grief

Theories have been proposed to promote understanding of the grieving process and individual responses to death (Stroebe, Hansson et al., 2007). These theories contribute to our understanding of reactions and responses to bereavement, as well as highlighting the complexity of the process and difficulties that can present (Stroebe et al., 1993). One of the earliest contributions to the study of grief was proposed by Freud (1917). Adopting a psychoanalytic perspective, Freud stated that individuals form close bonds with others and when the person dies, great effort is needed to let go of the attachment to the deceased individual. Through time and the process of grieving, the individual is able to break this bond and move on to form new relationships.

Another highly influential theory of grief is that of attachment proposed by Bowlby (1961). Attachment is described as the early development of strong affectional bonds with other individuals that promote feelings of safety and security (Bowlby, 1977). Grief is described as a form of separation anxiety that occurs when a bond with an attachment figure is broken. Grieving is, therefore, considered to be a universal response to separation, which manifests as distress and through the display of intense emotional reactions.

Alternative theories of grief include stress theories (Horowitz, 1986; Lazarus & Folkman, 1984), which propose that bereavement is a stressful life event. These theories emphasise the impact of stress on an individual's physical well being and offer an explanation for the relationship between bereavement and health outcome. Psycho-social transition theory (Parkes, 1996) proposes that a major loss can lead an individual to question their assumptions about themselves, others and the world. As an example, if an individual believes that the world is good and bad things do not happen to good people, bereavement can create discrepancies between these assumptions and events that occur, resulting in feelings of fear and insecurity.

1.1.2 The Process of Grieving

The normal expectation following bereavement is for an individual to grieve, however, the manner and degree to which this is expressed is an individualised process and will vary according to societal expectations and cultural traditions (Simos, 1979). There is considerable debate about the time course of normal grief (Schuchter & Zisook, 1993). Historically, it was argued that the acute distress

following bereavement should subside within weeks or months (Engel, 1961; Lindemann, 1944). More recently, the literature has questioned the concept of resolution of grief, instead describing grieving as an ongoing process, which may not reach a definite conclusion (Payne et al., 1999; Rubin, 1996). A further development was proposed by Klass et al. (1996) who challenged the idea that grieving requires an individual to break all bonds with the deceased in order to move on and form new attachments. The authors proposed that the purpose of grieving is to retain a lasting bond with the deceased that does not hinder the development of new relationships.

1.1.2.1 Normal Grief Responses

Bereavement is a significant life event resulting in a wide range of grief responses (Kim & Jacobs, 1991; Rando, 1993). As the list of reactions to bereavement is so extensive and varied, researchers have attempted to categorise them. Typical reactions to bereavement can be grouped into cognitive, emotional/affective, behavioural and physiological (Hansson & Stroebe, 2006; Stroebe, Schut et al., 2007; Worden, 2003). Emotional responses to bereavement may be characterised by anger, sadness, anxiety, loneliness, fatigue, shock, yearning and relief. Physiological sensations may include loss of appetite, sleep disturbance, lack of energy and somatic complaints. The cognitive responses may be displayed by confusion, rumination, disbelief, preoccupation with thoughts of the deceased, sense of presence and helplessness. Finally, behavioural responses may include social withdrawal, restlessness, searching for the deceased and crying.

1.1.2.2 Models of Grief

The interest in the process of grieving has led researchers to identify common reactions that are displayed by grieving individuals and these have informed the development of models of grief (Bowlby, 1969; Freud, 1917; Kubler-Ross, 1969; Lindemann, 1944; Parkes, 1996). These models generally hypothesize that bereavement leads to an initial period of shock characterised by numbness, disbelief and denial, leading to yearning, disorganisation and despair before resolution, adjustment and acceptance of the loss can occur.

The tendency to view the grieving process in terms of stages or phases has been criticised for portraying each component as fixed and orderly with rigid boundaries and with no regard for individual variation in grieving (Averill & Nunley, 1993, Schuchter & Zisook, 1993; Worden, 2003). Parkes (1993) stressed the importance of individuality when considering the grieving process, stating that individuals should not be forced into predetermined models but that these should be used as a guide for an individual's progress.

In order to address this, Worden (2003) proposed a concept termed the 'tasks of grieving', which it has been argued is a more useful concept for clinicians (Read, 2003). These tasks take account of the active process of grieving, whereby the mourner has an active role in accomplishing certain tasks in order to resolve their grief and move on (Leick & Davidsen-Nielsen, 1991; Luchterhand & Murphy, 1998; Worden, 2003).

Worden's (2003) four task model is outlined below. Task one is focused on accepting the reality of the loss in which the person is required to acknowledge and accept the person is dead and will not return. The second task involves experiencing the pain of grief. It is common for individuals to experience physical, emotional and behavioural pain following a death and again this is considered essential to move on to the next task. Task three highlights the need to adjust to an environment without the deceased. An individual might have to adjust to changing roles, which may require the development and acquisition of skills to fulfil these responsibilities and successfully complete this task. Task four is concerned with finding a suitable place for the deceased in ones emotional life in a way that enables the person to move on and complete the grieving process.

In addition to this approach, another recent model called the dual process model (Stroebe & Schut, 1999) has been proposed. This model recognises that both expressing and controlling feelings of grief are important and describes the process of bereaved individuals moving backwards and forwards between grief and restoration work. While previous models have focused on loss and the need to express grief to avoid further difficulties, the authors suggest that in certain circumstances avoiding grief may actually be a helpful process. Within this model, grief is viewed as a dynamic process that alternates between focusing on the loss of the person who has died (loss orientation) and avoiding it (restoration orientation), both of which are considered necessary for adjustment. Loss orientation involves traditional grief work while the restoration orientation involves dealing with

additional losses that occur as a result of the death, for example adopting roles previously undertaken by the deceased.

1.1.2.3 Rituals Surrounding Death

The grieving process and adjustment to loss is also influenced by cultural traditions and the social context in which it occurs (Raphael, 1984). Bereavement rituals have been customary in society for generations (Averill, 1968; Clark, 2000). Rituals vary according to culture, societal expectations and religion, and help provide a framework to give meaning to death and subsequent adjustment (Raphael, 1984). Each culture possesses its own beliefs, customs and behaviours to acknowledge a death and remember the deceased, for example, religious ceremonies and funeral rites (Schuchter & Zisook, 1993). Consideration of an individual's religious beliefs and cultural values is thought to be very important as they will likely influence the response to bereavement, including its duration and expression (Romanoff & Terenzio, 1998; Stroebe & Schut, 2007).

1.1.3 Risk Factors in Bereavement Outcome

Increasing attention has been paid to the identification of risk factors in bereavement outcome, which has important implications for prevention of difficulties and recovery from grief (Fisher & Warman, 1990; Sanders, 1993; Stroebe & Schut, 2007). A risk factor is defined as an individual characteristic or an environmental feature that can increase propensity to developing psychiatric or health related conditions (Last, 1995). The recognition of such factors is important in understanding why bereavement affects individuals in different ways, specifically

why some appear to cope relatively well while others experience intense and enduring outcomes (Hansson & Stroebe, 2003).

Grief has been associated with increased risk for the development of a variety of psychiatric and physical health complaints (Averill & Nunley, 1993; Parkes, 1993). While the majority of bereaved individuals cope with and adjust to loss without the need for specialist intervention, some individuals experiences difficulties that may require professional help (Kim & Jacobs, 1991; Kristjanson et al., 2006; Raphael, 1984; Schuchter & Zisook, 1993). This is an important area of research as the early identification of individuals who are at risk can assist in reducing potential demands that are placed on healthcare professionals and also improve the outcome for the bereaved (Stroebe & Schut, 2007).

Within the literature, there is considerable variation in the categorisation of risk factors. There is, however, general agreement that risk factors should include those associated with the death and those related to the bereaved individual including; circumstances of the death, relationship and attachment to the deceased, personality style, social support and additional stresses (Parkes, 1996; Raphael, 1984; Sanders, 1993; Stroebe & Schut, 2007; Worden, 2003).

With regards to the relationship and attachment to the deceased, the literature states that the nature and quality of the relationship can impact on bereavement outcome (Bowlby, 1980; Glick et al., 1974; Parkes & Weiss, 1983; Raphael, 1984; Sanders, 1993; Stroebe et al., 2005). This may be dependent on childhood experiences and

the presence of healthy attachment styles (Bowlby, 1980). It has been stated that those with secure attachments to others may be more able to resolve their grief and move on, whereas those without secure attachments may have greater difficulty adjusting to a loss (Stroebe, 2002). It has also been argued that the death of an individual with whom the bereaved had a very close or dependant relationship can create greater distress and potentially have a negative effect on bereavement outcome (Raphael, 1984; Weiss, 1974).

The circumstances of the death is another risk factor that can impact on the outcome of bereavement. Traditionally, deaths have been categorised under four types; natural, accidental, suicidal and homicidal, and bereavement outcome can depend on proximity, whether the death was anticipated and number of losses suffered (Worden, 2003). As an example, the death of a child in an accident will impact on the course of bereavement differently to an older individual who dies following a long illness. Taking into account stress and attachment theories, it has been argued that a sudden death is more stressful than one that is expected, due to the impact it has on an individual's wellbeing and their feelings of safety and security (Stroebe & Schut, 2007). There is inconsistent research on the impact of a sudden loss with some finding it to have a negative effect on bereavement outcome (Ball, 1977; Parkes, 1975; Sanders, 1983), but others finding no such evidence (Breckenridge et al., 1986; Maddison & Walker, 1967). Stroebe and Schut (2007), however, argue that this discrepancy could be explained by the individuality of the grieving process and distinct variations in grief responses.

There are also risk factors associated with the individual including personality traits, age, coping style and the presence of psychiatric disorders (Stroebe & Schut, 2007; Worden, 2003). While there has been less research in this area, it has been suggested that stressful life events will have a greater impact on those who are less well adjusted, have a negative outlook on life and adopt passive coping strategies (Raphael et al., 2007; Worden, 2003). Another important indicator is how an individual has coped with previous losses, as prior difficulties following bereavement or unresolved grief can impact on the current grieving process (Walsh & McGoldrick, 1988). The presence of psychiatric disorders including clinical depression, panic disorder and generalised anxiety disorder, may also increase vulnerability to developing complicated grief reactions (Kim & Jacobs, 1991; Parkes & Weiss, 1983).

Another widely accepted factor is that of social support. It has been stated that a lack of social support can increase risk, whereas an available support network can protect an individual from a negative bereavement outcome (Stroebe & Schut, 2007; Stylianos & Vachon, 1993). It has been suggested that access to social support can protect an individual and facilitate the grieving process by reducing isolation and distress (McCallum et al., 1993; Rook, 1987; Rosenblatt & Burns, 1986). A lack of social support, therefore, has the potential to intensify the impact of bereavement and hinder the recovery process (Stylianos & Vachon, 1993). Research has also demonstrated that progression through the grieving progress can take longer in those who are more isolated and dependant on fewer individuals (Clayton, 1975; Lake, 1984; Stylianos & Vachon, 1993). There is, however, limited empirical support for

the role of social support in bereavement outcome and inconsistent findings in the research (Stroebe, Schut et al., 2007).

Also, circumstances following the loss are important for determining bereavement outcome. Death can create a high level of disruption and result in additional losses for the individual, for example, financial worries and a deterioration in physical health (Sanders, 1993). Multiple crises following bereavement have been associated with an increased risk of developing additional complications (Parkes, 1975).

While the research has identified potential risk factors for bereavement outcome, there are limitations within the studies conducted. Many studies lack the inclusion of a non bereaved control group, which raises the question of whether certain risk factors are general (also applicable to non bereaved individuals) or specifically related to bereavement (Stroebe & Schut, 2007). The exact course of grieving cannot be predicted or assumed and it is, therefore, necessary to consider the wider circumstances of death and the combination of individual and environmental factors that may determine outcome (Stroebe & Schut, 2007).

1.1.4 Complicated Grief

The difficulties with defining normal grief and its process are compounded when considering grief reactions that do not follow the expected course (Middleton et al., 1993). While a considerable amount of research has been conducted into normal grieving, with its course and progression now being more fully recognised, it has

taken a great deal longer for investigations into the manifestation and impact of complicated grief to be conducted (Stroebe et al., 2000).

1.1.4.1 Theories of Complicated Grief

Theories of complicated grief have been proposed, with psychoanalytic and attachment theories offering significant contributions to the understanding of this process. In 1917, Freud wrote an article titled "*mourning and melancholia*" in which he concluded that pathological grief developed as a result of ambivalence in the relationship between the bereaved and the deceased. Alternatively, Bowlby (1980) proposed that pathological grief was related to childhood experiences. Within his studies on attachment styles, Bowlby (1977) identified three disordered forms of attachment; anxious, avoidant and disorganised, which can impact on the development of healthy relationships and lead to difficulties with the grieving process. There is, however, still little agreement on definition and of what is considered to represent normal and pathological grieving.

Subtypes representing the variation from normal grief include absent (Deutsch (1937), delayed and distorted (Lindemann, 1944), inhibited (Parkes, 1965), chronic, masked and exaggerated (Worden, 2003) and unresolved (Zisook & Lyons, 1991). It has, however, been argued that this form of grieving can be more accurately described as complicated grief as opposed to using subtypes, which are often vague and lack empirical support (Prigerson & Jacobs, 2007; Prigerson & Maciejewski, 2006). For the purpose of this study, the term complicated grief will be used to

describe the grieving process which differs from normal grief as this is a commonly used term within the literature.

1.1.4.2 Complicated Grief Reactions

A complicated grief reaction has been defined as grief that deviates from the expected course, according to cultural and societal expectations, in which symptoms may be longer lasting or delayed and emotional reactions more intense or absent (Averill, 1968; Kim & Jacobs, 1991; Middleton et al., 1993; Parkes, 1996; Worden, 2003). This is particularly important as complicated grief reactions have been recognised as a precursor for a variety of physical and mental health disorders (El-Jawabri & Prigerson, 2006).

Researchers have identified indicators that an individual may be experiencing a complicated grief reaction (Lazare, 1979; Rando, 1993). Complicated grief is often evidenced by frequent conversation centred on loss, intense grief reactions triggered by insignificant events, preserving the environment of the deceased, imitation of the deceased, subclinical depression, drastic lifestyle changes and fear of death. Individuals suffering complicated grief reactions also appear to exhibit ongoing difficulties in employment and relationships along with a reduced interest in their own life (Prigerson & Maciejewski, 2006).

1.1.4.3 Differentiating Complicated Grief from Psychiatric Disorders

Research has raised the question about an overlap between grief and psychiatric disorders, as the profound manifestations of grief often resemble symptoms of

psychiatric disorders (Middleton et al., 1993; Simos, 1979). Many difficulties commonly associated with psychiatric disorders are evident in the early stages of grief, including anxiety, low mood and anger, but are considered to be normal aspects of the grieving process (Parkes, 1996). Research has, however, identified complicated grief as distinct from psychiatric disorders including, depression (Ogrodniczuk et al., 2003; Prigerson et al., 1996), post traumatic stress disorder (Prigerson et al., 1999) and anxiety disorders (Boelen et al., 2003). Complicated grief is not yet recognised as a diagnostic category within any diagnostic manuals. There is, however, growing interest in its inclusion as a diagnostic category in its own right that is separate from other psychiatric disorders (Boelen et al., 2003; Horowitz et al., 1997; Jacobs et al., 2000; Prigerson et al., 1997; Prigerson et al., 2008).

1.2 BEREAVEMENT, GRIEF AND LEARNING DISABILITY

Individuals with learning disabilities have often been denied the same opportunities that are available to the general population, for example being denied the right to vote and being excluded from discussion about sexuality and relationships (Blackman, 2003). This is also applicable to bereavement, in which the needs and rights of individuals with learning disabilities have often been neglected and misunderstood (Oswin, 1991). Despite gradual advancements and increased recognition of bereavement issues in this client group, it remains less researched than other areas.

1.2.1 Learning Disability

A learning disability is a lifelong condition that may occur as the result of genetic or developmental factors, or as a result of brain damage suffered before reaching adulthood. While the terminology used to describe this condition varies widely, the term currently adopted within the United Kingdom is that of learning disability. Individuals with a learning disability do not represent a homogenous group, but a diagnosis is made based on three criteria: onset occurring prior to adulthood, significant impairment in intellectual functioning and significant impairment in adaptive or social functioning (American Psychiatric Association, 1994; The British Psychological Society, 2000). According to the Diagnostic and Statistical Manual of Mental Disorders-IV-Text Revision (APA, 2000), individuals with learning disabilities are also classified as mild, moderate, severe or profound dependant on the level of impairment.

1.2.1.1 Demographics and Changing Lifestyles

The number of individuals with a learning disability in the United Kingdom has increased over the past thirty five years and it has been estimated that there are one hundred and twenty thousand individuals with a learning disability living in Scotland (Scottish Executive, 2000). Historically, many individuals with learning disabilities were cared for in hospitals and large institutions. Huge advances in policy and legislation for this group of individuals have led to significant changes, particularly through an increase in community based living opportunities (Department of Health, 1989). Improvements in health care and living conditions have also significantly increased the life expectancy of individuals with learning disabilities (Blackman,

2003; Holland, 2000). This has resulted in an increased demand for carers and support staff and the need for services to address the needs and requirements of this client group more than ever before (Caine et al., 1998; Scottish Executive, 2000).

Research has focused on the move from institutional living to care in the community, but less attention has been paid to the emotional issues or needs that may be associated with this (Bennett, 2003). Approximately sixty per cent of individuals with learning disabilities live at home with their families and a third of such informal carers are aged over seventy (Department of Health, 2001). Plans for future care are often lacking (Prosser, 1997), which are vital given that individuals with learning disabilities are now more likely to experience bereavement during their lifetime (Blackman, 2003; Crick, 1988; Holland, 2000).

1.2.1.2 Normalisation

The principle of normalisation has been applied to grief and learning disability (Oswin, 1991). The main premise behind normalisation was to ensure services, for those considered to be devalued in society, meet individual need adequately and appropriately (Wolfensberger, 1972). Oswin (1981) applied this principle to bereavement stating that individuals with learning disabilities pass through the same stages of grief as the general population, are deserving of consideration, have the right to grieve and to receive specialist help should they present with particular difficulties.

1.2.2 Bereavement and Learning Disability

Individuals with learning disabilities are the *"most vulnerable and socially excluded in our society"* (Department of Health, 2001). This is particularly evident at a time of bereavement, when their grief may not be recognised with symptoms of distress attributed to their learning disability as opposed to a common response to loss (Read & Elliott, 2003). These individuals have often been intentionally excluded from bereavement, whether due to disregard of their feelings or as a means of protecting them from the painful experience of death (Read & Elliott, 2003). There is, however, no evidence to support the assumption that the presence of a learning disability precludes a reaction to death (Oswin, 1985; Palazon, 1991).

It is no longer considered ethical to protect individuals with learning disabilities from significant life events, such as bereavement, and the need for further research in this area has long been advocated (Oswin, 1991). Historically, there existed a commonly held assumption that individuals with learning disabilities did not understand death and were, therefore, incapable of grieving (Oswin, 1991). Kitching (1987) stated that preconceptions and stereotyped views can prohibit the understanding and acknowledgement of grief in individuals with learning disabilities. The work by Oswin and other researchers has challenged these assumptions and led to a gradual change in understanding and attitudes about this important area. Within the literature, it has been stated that a limited cognitive capacity (Kitching, 1987; Wadsworth & Harper, 1991), limited emotional capacity (Cochrane, 1995; Oswin, 1992) and limited understanding of grief reactions (Kitching, 1987; Wadsworth & Harper, 1991), are all factors attributed to individuals with learning disabilities that

can contribute to the assumption they are unable to grieve. Death itself is considered a taboo subject and one which many are not comfortable talking about or dealing with (Conboy-Hill, 1992). This combined with the stigma of having a learning disability, which can also be something that individuals would rather ignore or shy away from than address, can create a double taboo at times of bereavement (Brelstaff, 1984; Kitching, 1987).

1.2.3 Grief Reactions in Individuals with a Learning Disability

Within the research that has been conducted, attention has been paid to identifying grief reactions displayed by individuals with learning disabilities (Bonell-Pascual et al., 1999; Dodd, Dowling et al., 2005; Dowling et al., 2006; Emerson, 1977; Harper & Wadsworth, 1993; Hollins & Esterhuyzen, 1997; MacHale & Carey, 2002; Wadsworth & Harper, 1991). Research has clearly demonstrated that individuals with learning disabilities do suffer bereavements (Service et al., 1999), are capable of grieving (Clarke & Read, 1998; Dodd, Dowling et al., 2005), appear to pass through the same stages or phases of grief (Carder, 1987) and often respond to death in a manner similar to the general population (Harper & Wadsworth, 1993; Oswin, 1989). Within this group of individuals, however, there will be differences in level of ability and previous experiences, which may impact on reactions to bereavement (James, 1995).

Grief has been shown to be a major contributing factor to a wide range of behavioural and mental health problems in individuals with learning disabilities (Bonell-Pascual et al., 1999; Conboy-Hill, 1992; Day, 1985; Dodd, Dowling et al.,

2005; Emerson, 1977; Hollins & Esterhuyzen, 1997; MacHale & Carey, 2002; McLoughlin & Bhate, 1987; Ray, 1978). Hollins and Esterhuyzen (1997) carried out a systematic study of fifty bereaved individuals with learning disabilities and compared them with a matched control group. The authors found significant differences between the two groups on measures of aberrant behaviour and psychopathology. The bereaved group displayed increased irritability, lethargy and hyperactivity on a measure of aberrant behaviour, which were considered to represent behavioural expressions of grief. In addition to this, the authors also found significant differences on a measure of psychopathology with the bereaved group presenting with depression, anxiety and adjustment disorders. A follow up study was conducted to investigate if these difficulties were still present five years later (Bonell-Pascual et al., 1999). The findings showed a slight increase in aberrant behaviour in the bereaved individuals but improvements in mental health were evident. It was concluded that individuals with learning disabilities experience bereavement responses similar to the general population, however, the expression of grief may differ. One limitation was that the non bereaved control group were not included in the follow up study to allow further comparisons to be made.

Dodd, Dowling et al. (2005) conducted a systematic review of the literature to investigate the emotional, psychiatric and behavioural responses to bereavement in individuals with a learning disability. The authors concluded that bereavement has a distinct effect on individuals with learning disabilities, with noticeable behavioural changes and increases in depression and anxiety symptomatology. This study also highlighted the difficulties in researching this area with particular reference to the

lack of standardised measures that exist for this population and a reduced focus on self report.

In addition to these grief responses, Cathcart (1994a) identified a number of non verbal expressions of grief commonly seen within this population, including clinginess, uncharacteristic incontinence, self injurious behaviour, restlessness, clumsiness and reluctance to go out.

Emerson (1977) investigated referrals received for emotional and behavioural management difficulties in order to identify potential precipitants. She found evidence of bereavement in half of the referrals received prior to the onset of symptoms. Emerson concluded that staff/carers may deny the significance of the bereavement and respond inappropriately by not offering time to grieve or misdirecting feelings. These are all factors that can contribute to disenfranchised grief as described by Doka (1989). Disenfranchised grief occurs when grief is not recognised, the significance of the relationship between the deceased and the griever is not acknowledged and the griever themselves is disregarded.

One of the most significant findings from the research is the identification that grief is often misunderstood with behaviour or emotional responses being attributed to other factors and, therefore, being dealt with inappropriately (Bonell-Pascual et al., 1999; Dodd, Dowling et al., 2005; Emerson, 1977; Harper et al., 1991; Hollins & Esterhuyzen, 1997). This may lead to individuals with learning disabilities being referred to specialist services with no recognition of the link between the

presentation and grief response, which could result in inappropriate treatment being offered. This is a vitally important area given the potential difficulties and additional problems that may arise when grief is not recognised or acknowledged.

Research has identified that bereavement has a distinct impact on the behaviour and mental health of individuals with learning disabilities (Bonell-Pascual et al., 1999; Dodd, Dowling et al., 2005; Emerson, 1977; Hollins & Esterhuyzen, 1997). In addition to this, studies have identified that bereaved individuals with learning disabilities experience significantly more life events following bereavement, for example having to move to new accommodation (Bonell-Pascual et al., 1999; Hollins & Esterhuyzen, 1997). It is recognised within the literature that additional disruption and changes after bereavement can create further difficulties for the bereaved individual (Parkes, 1975). One of the major limitations within the research conducted, therefore, relates to the difficulty in differentiating between bereavement reactions and reactions that occur as a consequence of additional losses faced by the bereaved individual. The studies conducted generally adopt a quantitative approach, utilising assessment measures to gather information on symptoms of psychopathology and behavioural difficulties that may represent bereavement reactions. This data in isolation, however, makes it difficult to dissociate the effects of bereavement from reactions to other life events. Further research, possibly adopting a qualitative approach, would be beneficial to distinguish bereavement reactions from those associated with additional losses that occur as a result of the bereavement.

1.2.4 Learning Disability and Complicated Grief

Within the research conducted, there remains a lack of understanding and consensus about the grief symptoms displayed by individuals with learning disabilities and what represents normal or complicated grieving (Dodd, Dowling et al., 2005; Hollins & Esterhuyzen, 1997; Kristjanson et al., 2006). It has been suggested that learning disability is a predictor of complicated grief (Bonell-Pascual et al., 1999) and, along with other factors, difficulties can occur if grief is not sufficiently recognised or expressed following bereavement (Emerson, 1977). Limited research has, however, been conducted to accurately describe the presentation and specific symptoms of complicated grief in individuals with a learning disability (Dodd, Dowling et al., 2005).

A recent study was conducted by Dodd et al. (2008) to examine symptoms of complicated grief in individuals with learning disabilities. Carers of individuals with learning disabilities who had experienced parental bereavement in the previous two years completed a bereavement history questionnaire and a newly developed measure to examine symptoms of complicated grief. The results were compared with a matched control group and the findings suggested that one third of the bereaved group exhibited a large number of complicated grief symptoms. A surprising finding was that complicated grief symptoms were more evident in those individuals who had greater involvement in bereavement rituals, which conflicts with the widely accepted notion that involvement in rituals can be beneficial to bereaved individuals with learning disabilities (Dodd, McEvoy et al., 2005). This study was, however, conducted with a small sample of individuals who had suffered parental

bereavement within the previous two years and specific details of when the deaths had occurred were not reported. It has been stated that symptoms of grief should diminish for the majority of individuals within one to two years after bereavement (Dodd, McEvoy et al., 2005). On the basis of this, it could be argued that it may be more beneficial to assess for symptoms of complicated grief when the two year time frame has elapsed. In addition to this, the study focused on carer based assessment, thereby relying on third party report of presenting symptoms.

1.2.5 Factors Influencing Bereavement Outcome

A learning disability does not prevent an individual from experiencing normal bereavement reactions; however, it can increase the risk of additional difficulties (Day, 1985; Emerson, 1977; Oswin, 1985). Individuals with a learning disability are also more vulnerable to developing difficulties as a result of others failing to recognise their grief and respond appropriately (Kloeppel & Hollins, 1989; Oswin, 1989). Previous sections have identified possible factors that can mediate the grieving process including prior life experiences and the nature of the relationship with the deceased, which are applicable to all individuals. For individuals with learning disabilities, additional factors can also further complicate the grieving process, for example the presence of cognitive impairment and communication difficulties (Vredeveld, 1985).

1.2.5.1 Cognitive Ability and Concept of Death

Understanding of death is said to develop throughout childhood, with increased recognition and acceptance of its universality and inevitability as people age

(Raphael, 1984). To research understanding of death, a study was conducted by Kane (1979) on children of average intelligence. The children were asked questions based on the main components of the concept of death, including, realisation, separation, causality, dysfunctionality and universality. Kane concluded that awareness of these components was gradually attained by children, in line with Piaget's model of cognitive development.

There is considerably less research on the development of the concept of death in adults with learning disabilities. It has been argued that the ability to understand death and therefore progress through the grieving process requires a certain level of intellectual ability (Bihm & Elliott, 1982; Sternlicht, 1980). Bimh and Elliott (1982) assessed seventy nine individuals with learning disabilities to determine their degree of understanding of death. They concluded that level of cognitive ability, as defined by Piaget's model, directly influences the development of the concept of death, rather than age. Individuals at the concrete operational stage appeared to have greater understanding compared to those at the preoperational stage, indicating that level of cognitive impairment is directly related to level of understanding.

Alternatively, researchers have found that understanding of death is dependent on age and life experience as opposed to level of intellectual functioning (Lipe-Goodson & Goebel, 1983; Seltzer, 1989). McEvoy (1989) found that those individuals with greater self care and community skills and fewer communication difficulties had more fully developed concepts of death. It has also been concluded that individuals with learning disabilities may have a poor understanding of the ageing process and

life cycle, which may impede the development of a full concept of death (Kloeppel & Hollins, 1989; McEvoy, 1989). A study was also conducted by McEvoy and Smith (2005) in which relatives of individuals with learning disabilities were asked about the grieving process and concept of death in individuals with learning disabilities. They found that eighty two per cent of the relatives reported that individuals with learning disabilities could not understand the concept of death. This suggests that relatives may underestimate the level of understanding in individuals with learning disabilities, highlighting the need for education on death and bereavement.

Regardless of these findings, it is unfounded to state that someone who does not understand the concept of death is, therefore, unable to feel or show their grief following a loss. While some individuals with learning disabilities may struggle with the more abstract components of the concept of death, they are still capable of recognising when significant others are missing and displaying emotional reactions to a loss, with no need for a full understanding of the meaning of death (Bradford, 1984; Dodd, Dowling et al., 2005; Harper & Wadsworth, 1993; Wadsworth & Harper, 1991).

1.2.5.2 Communication, Emotion Recognition and Expression

It has been stated that a significant proportion of individuals with learning disabilities will have some degree of communication difficulties (Kerr et al., 1996; Remington, 1998; Sigafoos et al., 2007). Limited communication skills can impede the natural process of grieving, by reducing the ability to express grief and verbalise feelings, which can compound the loss experience and leave the individual feeling frustrated

and isolated (Cathcart, 1991; Cochrane, 1995; Crick, 1988; Kitching, 1987; McLoughlin, 1986; Oswin, 1991). Where an individual has difficulties with communication, grief reactions or distress may be apparent through changes in behaviour or mood, as this may be the only means of expression (Blackman, 2003; McLoughlin, 1986; Moddia & Cheung, 1995). Communication deficits can also create further difficulties if the deceased was the main person with whom the individual could communicate (Cochrane, 1995; McLoughlin, 1986), which may create difficulties for staff in understanding the individual's needs (Kerr et al., 1996).

More recently, research has been conducted on emotion recognition and expression in individuals with learning disabilities (Arthur, 2003). The ability to recognise emotions is thought to be important for social interaction (Stewart & Singh, 1995) and difficulties in emotion recognition and expression can have negative consequences for interpersonal relationships and social functioning (Owen et al., 2001; Robbins & Hall, 2003). Given that some individuals with learning disabilities will have difficulties with verbal communication, they may find it hard to convey their feelings and emotional state to others (Reed & Clements, 1989), which could place the individual at increased risk following bereavement (Day, 1985; Hollins & Esterhuyzen, 1997; McLoughlin, 1986). An inability to recognise emotional responses in individuals with learning disabilities has been shown to be predictive of behavioural and mental health difficulties (Matson & Sevin, 1994). It has, therefore, been stated that in order to understand and make sense of changes in the individuals they are supporting, staff need to be able to recognise and identify non verbal methods of communication (Blackman, 2003).

1.2.5.3 Comorbidity

In addition to the difficulties mentioned in the previous section, other conditions, for example sensory impairments, challenging behaviour and psychiatric disorders, often occur concurrently with learning disability (Hatton, 1998). It has been stated that individuals with learning disabilities who have additional physical and/or sensory impairments may have difficulty understanding verbal explanations of a loss, which can create further problems (Oswin, 1991). In addition to this, certain diagnoses, for example dementia (Doka, 2004) and autistic spectrum disorders (Rawlings, 2000) can also serve to complicate the grieving process. While having a learning disability appears to increase the likelihood of the individual being excluded from death, the presence of additional conditions can further increase this probability (Read & Elliott, 2003).

1.2.5.4 Degree of Dependence and Social Support

Individuals with learning disabilities often have restricted support networks and their relationships with others may be characterised by strong attachments and high levels of dependency (McLoughlin, 1986). Within a closed or limited network, the loss of a significant relationship can have a greater impact and create distress for all individuals concerned (Stylianos & Vachon, 1993). As an example, the death of an individual who was the main provider of instrumental and emotional support can have devastating effects and possibly increase the likelihood of complicated grief (Delorme, 1999; Middleton et al., 1993).

Studies have also shown that increased levels of distress one month after bereavement are often found in individuals who have limited contact with close friends and family (Vachon, 1979). Limited support at time of grief has been associated with negative bereavement outcome, for example resulting in a decline in physical health that may require medical intervention (Maddison & Walker, 1987; Raphael, 1984). This clearly highlights the value of a sufficient support network following bereavement. Social interactions can, however, have a negative effect and create further distress if, for example such situations are not dealt with openly and sensitively (Gottlieb, 1983; Wortman & Silver, 1989). For people who live within residential settings, bereavement can have a dramatic impact on a greater number of individuals. A bereavement that impacts on a wider network may also result in individuals being unable to offer support to those most affected by the death (Stylianos & Vachon, 1993).

1.2.5.5 Multiple Losses

Within the general population, it is recognised that bereavement can generate many additional losses for an individual (Leick & Davidsen-Nielsen, 1991). Individuals with learning disabilities may also experience a profound degree of disruption in their lives following bereavement, including loss of their home, possessions, security, routine and familiarity, possibly all within a short space of time (Bonell-Pascual et al., 1999; Cochrane, 1995; Crick, 1988; McLoughlin, 1986; Oswin, 1992; Palazon, 1991). The capacity to cope with these changes and disruption is one that would challenge many individuals while working through bereavement and could

potentially increase the propensity to developing complicated grief (Kitching, 1987; Luchterhand & Murphy, 1998; McLoughlin, 1986).

1.2.5.6 Lack of Preparation for a Loss and Exclusion from Bereavement Rituals

Historically, it was not uncommon for a death to be concealed from individuals with a learning disability and more importantly, they were not provided with information about an impending death in order to help them prepare for the inevitable (Hollins & Esterhuyzen, 1997; Stoddart et al., 2002; Wadsworth & Harper, 1991). Lack of preparation for bereavement can further increase the likelihood of multiple losses after a death, for example having to move home if they previously lived with a family member (Bowey & McGlaughlin, 2005). In a study by Strachan (1981), he found that individuals with learning disabilities had a significant reduction in their contact with terminally ill relatives during their illness, thereby offering no opportunity to prepare for the impending death. This significant finding has also been replicated in more recent studies (e.g. Hollins & Esterhuyzen, 1997). Being denied the opportunity to prepare for a death can also increase the likelihood of an individual experiencing a sudden death (O'Nians, 1993), which has been demonstrated to be more traumatic, with the propensity to prolong the grieving process (Sanders, 1989; Wright, 1992).

Historically, there was a tendency for those with learning disabilities to be denied the opportunity to participate in mourning rituals in order to shield them from the emotional pain and sadness this can create (Hollins & Esterhuyzen, 1997; Raji et al.,

2003; Wadsworth & Harper, 1991). It has been suggested that participation in mourning rituals can directly influence an individual's ability to adjust to a loss and move on after bereavement (Palazon, 1991). Rituals are considered important as they offer social support, an opportunity to say goodbye to a loved one and acknowledge the person will not return (Crick, 1988). Participation in bereavement rituals has also been shown to reduce repetitive questions about the location of the deceased and the presentation of problematic behaviours (Sheldon, 1998). In a more recent study, however, a greater number of complicated grief symptoms were evident in individuals with learning disabilities who had been involved in bereavement rituals (Dodd et al., 2008). Despite this, it has been suggested that withholding information about a death or denying the individual with a learning disability the opportunity to participate in bereavement rituals may impede the acceptance and expression of grief, which could in turn contribute to the development of complicated grief (McLoughlin, 1986; Raji et al., 2003; Read & Elliott, 2003).

1.3 SUPPORTING AN INDIVIDUAL WITH A LEARNING DISABILITY THROUGH BEREAVEMENT

Following the recognition that bereavement and learning disability is an area deserving greater consideration, there has been an increase in literature and research about offering support to individuals with learning disabilities at such times. Historically, when an individual with a learning disability suffered bereavement, the routine response by professionals was to offer medical intervention or behaviour therapy (Crick, 1988; Day, 1985; Emerson, 1977). This may reduce the intensity of grief reactions, but disregards the need for developing coping skills and working

through the grieving process (Crick, 1988; Moise, 1985). Unfortunately, inappropriate responses to bereavement are still evident, which may represent a continuing desire to protect an individual or lack of understanding in how to manage the situation appropriately (Cochrane, 1995; Oswin, 1991).

It has been stated that all staff who work with individuals with learning disabilities need to be committed to supporting them through the process of bereavement and adjusting to the loss (Messinger et al., 1986). Professional carers who work with individuals with learning disabilities are often young females who may have limited personal experience of bereavement (Read & Elliott, 2003). Offering support at a time of bereavement can be both difficult and challenging (Copp, 1999), and carers often receive little education or training to prepare them for dealing with bereavement in the individuals they support (Read & Elliott, 2003). Taking into account the above factors, it could be argued that staff may not be sufficiently prepared to offer support to an individual who has experienced bereavement.

Read and Elliott (2003) concluded that care staff require access to factual information, which can assist them in offering guidance and support following bereavement. Many authors also advocate the development of guidelines for staff to enhance service delivery and ensure consistent and appropriate services are offered to bereaved individuals with learning disabilities (Read, 2003; Read & Elliott, 2003). In spite of this recognition, some organisations that offer services to individuals with learning disabilities are failing to provide appropriate support for their clients at a time of bereavement (Murray et al., 2000). This could be due to the failure of staff in

recognising grief due to a lack of knowledge and understanding about bereavement in this group of individuals (Cochrane, 1995; Moddia & Cheung, 1995; Read, 1996). It could also be due to the impact it has on staff by reminding them of their own experiences of death (Read, 1996; Worden, 2003). These findings are concerning and can result in negative consequences for the bereaved individual they are supporting. It is, therefore, vitally important that staff working with these clients have the knowledge and skills to offer effective support at these times.

1.3.1 Knowledge of Staff Working with Individuals with a Learning Disability

It has been stated that a lack of knowledge about bereavement and grief can impact on the attitudes of staff and influence the support offered to bereaved individuals (Oswin, 1992). Unfortunately, there is still a tendency for carers, staff, family members and professionals to presume that individuals with learning disabilities are unable to comprehend the concept of death and grieve in a similar manner as the general population, which can impact on the support offered (Harper & Wadsworth, 1993; McEvoy & Smith, 2005; Moddia & Cheung, 1995). All individuals providing care and support to individuals with learning disabilities have a duty of care to protect them from harm; however, this does not include safeguarding them from the experience of death (Read & Elliott, 2003).

Previous research has been conducted on the knowledge of staff about the grieving process in individuals with a learning disability (Dodd, McEvoy et al., 2005; Murray et al., 2000). These studies found that the knowledge of staff about the grieving

process in individuals with a learning disability is generally quite good. Staff were able to recognise the emotional and behavioural impact bereavement may have on their clients and identified that individuals with learning disabilities should be informed of a death and given the opportunity to participate in bereavement rituals.

1.3.2 Preparation for Bereavement

It is recognised that the lack of opportunity to prepare for a death can have traumatic and devastating consequences for the bereaved individual, potentially leaving them vulnerable to developing complicated grief and subsequent physical and mental health difficulties (Kauffman, 1994). Preparation for bereavement is considered to be an important element of support (Crick, 1988) and it has been stated that individuals with learning disabilities can benefit from receiving education about death and dying (Luchterhand & Murphy, 1998; Yanok & Beifus, 1993). Preparation may involve discussions about the life cycle and the universal experience of death, which should occur before bereavement as well as at times of loss (Cathcart, 1991; Cochrane, 1995; Palazon, 1991). This could involve using general opportunities to educate the individual with a learning disability about loss, for example when the death of a well known person occurs (Cathcart, 1994a; Oswin, 1991). In addition to this, it has been stated that individuals with learning disabilities should be supported to remain in contact with relatives who are unwell in order to reduce the possibility of an unexpected and sudden death (Strachan, 1981).

It is no longer considered ethical or helpful to withhold information about a death (James, 1995; Kitching, 1987; Moddia & Cheung, 1995; Oswin, 1991). Staff may be

required to break the news of a death to a client and the manner in which this information is relayed to the individual with a learning disability, with regards to who provides the information and with how much detail, can have a major impact (Cochrane, 1995; Oswin, 1992). When breaking the news of a death to an individual with a learning disability, family members or staff should provide clear and truthful information and avoid the use of euphemisms, as this can create further confusion (Cochrane, 1995; Luchterhand & Murphy, 1998; Oswin, 1992). It has been stated that the decision as to who breaks the news of a death should be made on an individual basis and be someone who is in close contact and has a good relationship with the individual (Luchterhand & Murphy, 1998).

1.3.3 Participation in Bereavement Rituals

It has been suggested that some individuals in helping professions may disregard the cultural and religious values of clients (Purpura, 1985; West, 1997). Awareness and acknowledgement of cultural differences is important to avoid the assumption that ones own beliefs provide a sufficient basis for understanding and is an important component of offering effective and appropriate support at a time of bereavement (Clark, 2004). This includes offering encouragement to the individual with a learning disability to participate in rituals surrounding the death, as this has been shown to aid the grieving process and facilitate emotional release (Cathcart, 1991; James, 1995; Oswin, 1991). While no one should be forced to participate in such rituals, this process can often be hindered by others and denying an individual these opportunities can impact on the resolution of grief (Hollins & Esterhuyzen, 1997).

While there is limited evidence available, it has been stated that viewing the body of the deceased may help with the concept of death, for example, by confirming the reality of the death and appearance of the deceased, as well as offering a chance to say goodbye, which can help with acceptance of the loss (Cathcart, 1988). Research has also shown that deciding not to view the body is often a decision that an individual regrets at a later date (Finlay & Dallimore, 1991; Singh & Raphael, 1981). The decision to view the body requires careful consideration and should be made on an individual basis with sufficient preparation of the bereaved beforehand for what they are likely to see (Cathcart, 1988, 1994a).

1.3.4 Minimising Change

It is widely recognised that bereavement can result in multiple losses for individuals with learning disabilities, but the implications of this are often ignored or minimised (Cochrane, 1995). It has been argued that an individual's lifestyle and routine should be maintained as far as possible after bereavement as additional losses can intensify the grief experience (Crick, 1988; Kitching, 1987; McLoughlin, 1986; Oswin, 1991). Oswin (1991) recommended promoting stability as far as possible, in particular avoiding a sudden move to new accommodation and maintaining continuity of staff. She argued that it is beneficial for the person to be supported to remain within their home for a number of weeks until they can be gradually introduced to new and appropriate accommodation.

1.3.5 Social Support

Isolation at a time of bereavement can heighten feelings of distress and impact on the recovery process (Stroebe et al., 2005). Individuals with learning disabilities often have restricted social networks, which can increase the risk of negative bereavement outcome (McLoughlin, 1986). Supporting an individual with a learning disability who has experienced bereavement should involve facilitating access to existing support systems, as well as encouragement to build further relationships in order to widen their available support networks (Blackman, 2003; McLoughlin, 1986). Allowing the individual to spend greater periods of time away from parental homes can also help promote the development of new relationships (Cochrane, 1995).

1.3.6 Identification of Difficulties

It is important for staff and carers to recognise when an individual is not coping with a loss and identify when specialist help is required. Preventative interventions can be helpful to reduce negative outcomes in individuals with greater vulnerability to developing complications (Raphael, 1977). Professional input may, however, be necessary to help resolve difficulties in the grieving process or for those individuals suffering complicated grief reactions (Lindemann, 1944; Raphael, 1975). As mentioned in previous sections, for individuals with learning disabilities, there are a greater number of reasons why complications may occur (Bonell-Pascual et al., 1999; Hollins & Esterhuyzen, 1997). It is, therefore, important to recognise various factors that may hinder the grieving process, in order to ensure a referral is made to appropriate services at such times (Blackman, 2003; Kitching, 1987).

A number of factors have been identified that may precipitate the need for individuals with learning disabilities to seek specialist help (Elliott, 1995). This includes those individuals with high levels of anger, with limited or absent support networks, those exhibiting profound distress and yearning for the deceased and those who are failing to cope with the bereavement. It is also important to consider the length of the grieving process, intensity of grief reactions and the presence of risk factors, such as those mentioned in previous sections (Luchterhand & Murphy, 1998). In addition to this, Bowlby (1980) spoke about the need for staff/carers to possess adequate knowledge about complicated grief reactions and psychiatric disorder in order to distinguish between the two and decide if bereavement related intervention is necessary.

1.3.7 Facilitating the Grieving Process

Individuals with learning disabilities may require assistance from others to help them express their grief (Kitching, 1987). It has been suggested that a lack of knowledge and understanding, as opposed to intentional disregard, can lead carers to withhold information and exclude them from rituals to spare their clients with learning disabilities from upsetting and distressing events (Seltzer, 1985). Avoiding the topic of death can, however, create additional difficulties for carers to overcome if they are to offer appropriate and sensitive support at these times. Crick (1988) identified areas that need to be considered when offering support to an individual with a learning disability who has experienced bereavement. These include the use of communication techniques to assist them in expressing their grief, empathy, recognition of their feelings and need to grieve.

Techniques to facilitate the grieving process include tolerating repetition from clients to help them make sense of the loss, allowing sufficient time for the individual to grieve, normalising the reaction, identifying verbal and non verbal clues to feelings, respecting privacy and listening and offering the individual opportunities to talk about their feelings (Cochrane, 1995; Crick, 1988; James, 1995; Luchterhand & Murphy, 1998; Oswin, 1991; Read, 2003).

1.3.8 Creative Strategies

Grief therapy and counselling is widely utilised to assist bereaved individuals in coming to terms with a loss (Raphael et al., 1993). There is also a growing body of research evidencing the benefits of bereavement counselling, individual/group interventions and guided mourning for individuals with learning disabilities (Dowling et al., 2006; French & Kuczaj, 1992; Gault, 2003; Kitching, 1987; Mappin & Hanlon, 2005; Read, 1996, 2001, 2007; Read et al., 1999; Stoddart et al., 2002; Summers & Witts, 2003).

In addition to this, a bereaved individual with a learning disability may have specialist needs that may benefit from the use of creative approaches to educate them about death, enhance their understanding of the grief experience and aid communication (Read, 2003). This may include artwork, life story work (Hussain, 1997), memory boxes, story books, reminiscence therapy and pictorial work, which are particularly useful for individuals with additional communication difficulties (Read, 2003, 2007). There is also a relatively small, but useful, collection of

resources that can be utilised to support the bereaved individual with a learning disability through the grieving process (Cathcart, 1994a, 1994b; Cooley & McGauran, 2000; Hollins & Sireling, 1989, 1994, 1999; Hollins et al., 2003).

1.3.9 Support for Staff

Supporting a bereaved individual can be very difficult and it has been suggested that this can affect an individual in three ways: by increasing awareness of previous loss experiences, losses that may occur in the future and their own mortality (Worden, 2003). Limited knowledge and skills in staff can also create anxiety, emotional exhaustion and potentially impact on the quality of care provided (Bennett, 2003). In addition to this, carers may be affected by bereavement and need to grieve. It has, therefore, been suggested that along with access to factual information to assist staff in offering support to their client, they also have the opportunity to discuss their own attitudes and methods of coping with loss, as well as access to regular supervision and support from peers (Cathcart, 1991; Crick, 1988).

1.4 STAFF TRAINING

An important task for clinical psychologists working within the learning disability specialism is that of offering training to other staff members who provide care and support to individuals with learning disabilities (Noonan Walsh & Linehan, 2007; Sigafoos el al., 2007). It has long been recognised that staff who are employed to care for individuals with learning disabilities need to have relevant knowledge in order to identify behaviours and symptoms that could be indicative of mental illness or other potential difficulties (Zaman et al., 2007). It has also been argued that

possessing adequate knowledge can help reduce stress in staff members (Hatton, 1999; Holt & Oliver, 2000).

The delivery of good quality services for individuals with learning disabilities is said to be dependant on the knowledge and skills of staff working in these settings (Hastings, 1995; Rose, 1995). The benefits of staff training programmes to improve the knowledge and skills of staff working within learning disability services are also widely recognised (McKenzie et al., 2000; McKenzie et al., 2002). Within the literature on staff training, however, research suggests that a significant number of staff who work with individuals with learning disabilities have not received training and, of greater concern, those that have report it did not adequately prepare them to meet the demands of their job (Smith et al., 1996; McVilly, 1997).

The format of training programmes vary from those that are shorter and time limited (McKenzie et al., 2000; McVilly, 1997) to longer term courses offering ongoing input (Taylor et al., 1996). While there is sufficient evidence to demonstrate that staff training can improve knowledge (Allen et al., 1997; McKenzie et al., 2000), there is also evidence to suggest that, in isolation, training is not adequate to change practice in the long term (Cullen, 2000; Ziarnik & Bernstein, 1982). As staff training can generally be delivered over a short time period with minimal costs, it is often chosen as a preferred means of improving knowledge and confidence (Allen et al., 1997).

1.4.1 Staff Training on Bereavement in Individuals with Learning Disabilities

The benefits of providing staff and carers with information on death and bereavement have long been recognised, particularly with regards to improving knowledge and increasing understanding (Bennett, 2003; Feifel, 1977; Harper & Wadsworth, 1993; Rosenthal, 1981). It has also been suggested that training on bereavement should be mandatory for all individuals in professional and caring roles (Wass, 2004). Within support provider organisations, however, there is a lack of compulsory training for staff focusing specifically on bereavement in individuals with learning disabilities. Staff may, therefore, be supporting adults with learning disabilities who have suffered bereavement, while having no additional or specialist training in this area. Consequently, there may be implications for the ability of support staff to meet their legal and professional responsibilities for the individuals with learning disabilities that they support.

Those who are cared for by others are dependent on the skills of such individuals (Kerr, 1998) and it has been recognised that the response by others to the bereaved individual with a learning disability can create further difficulties, for example if the grief reaction is not recognised or acknowledged (Cochrane, 1995; Oswin, 1991). The importance of training on bereavement has been advocated for professionals, families, friends and carers, in particular to ensure they are adequately informed about grief and sufficiently prepared for such situations (Bennett, 2003; Cochrane, 1995; Harper & Wadsworth, 1993; Hollins & Sinason, 2000; Kitching, 1987; MacHale & Carey, 2002; McEvoy & Smith, 2005; Moddia & Cheung, 1995; Oswin,

1985). In addition to this, there is a recognised need for a more proactive approach to provide information to clients about death and dying to help prepare the individual for such experiences (Yanok & Beifus, 1993).

Within many of the studies conducted, recommendations include the provision of bereavement training for staff and carers working with individuals with learning disabilities (Harper & Wadsworth, 1993; Kloeppel & Hollins, 1989; Oswin, 1991). Training not only has the capacity to increase staff knowledge and skills (McKenzie et al., 2000) but also increase staff confidence in offering support at this difficult time (Reynolds et al., 2008). Carers with no experience of bereavement, personally or professionally, may lack knowledge about grief and could feel inadequate in offering support to bereaved individuals (Lake, 1984; Simos, 1979). Choosing to avoid or ignore bereavement and grief related issues will not protect a bereaved individual from emotional pain but adequate knowledge can help reduce distress and the risk of developing additional complications (Simos, 1979). While training packs have been developed providing information on supporting the general population (Goodall et al., 1994) and children (Holland et al., 2005) at a time of bereavement, there are very few training programmes specifically for staff working with individuals with learning disabilities (Crick, 1988; Neuberger, 1987; Oswin, 1992).

Within the relatively limited research that has been conducted on bereavement and individuals with learning disabilities, some attention has been paid to the provision of training for staff who currently work with this client group (Bennett, 2003; French & Kuczaj, 1992; Golding, 1991; Kauffman, 1994; Reynolds et al., 2008). Oswin

(1991) recommended that training courses be available for all professionals who work directly with this client group. It has been stated that training programmes need to include information on the grieving process and difficulties faced by those with learning disabilities, including their understanding of death (Harper & Wadsworth, 1993; Kauffman, 1994). Training should also provide staff with information on bereavement reactions, differentiating between normal and complicated grieving, along with information on how to support an individual through the grieving process and recognising when specialist intervention is required (Conboy-Hill, 1992; James, 1995; Read, 2003). It has also been suggested that having knowledge of factors that can influence the outcome of bereavement is essential to identify individuals at risk and develop appropriate support strategies (Parkes, 1985; Raphael, 1977). In addition to this, the topic of cultural or religious views are often overlooked on training courses dealing with bereavement, which can lead to a lack of knowledge and avoidance of these issues when offering support to bereaved individuals (Goldsworthy & Coyle, 2001; Neuberger, 1987).

1.4.2 Impact of Staff Training

There is limited research on the impact of educating support staff who work with adults with learning disabilities about bereavement and grief.

1.4.2.1 Impact on Knowledge

Bennett (2003) carried out a study to investigate the impact of loss and bereavement education on knowledge and understanding of carers for adults with learning disabilities. Adopting a qualitative approach the author conducted a needs

assessment interview with twelve carers to inform the development of an educational programme to raise awareness of bereavement issues. Of the twelve carers, nine reported receiving no prior teaching or education on bereavement and loss. Following the education provision, Bennett identified that carers demonstrated increased personal insight and greater ability to identify necessary changes to the care provision. The sample size within this study was, however, very small and the lack of statistical data makes it difficult to identify significant changes in knowledge and understanding.

1.4.2.2 Impact on Confidence

Only one study was found investigating the impact of training on the confidence levels of support staff working with individuals with learning disabilities. Reynolds et al. (2008) demonstrated that a two day training programme on bereavement and loss significantly increased the confidence of thirty three support staff about offering support to individuals with learning disabilities at a time of bereavement. A follow-up was, however, not conducted to assess the longer term impact of the training and determine if confidence levels were maintained.

1.5 SUMMARY

Bereavement in individuals with a learning disability is an under researched area. This is particularly concerning given the potential difficulties that could result for these individuals following bereavement. In the past it was often assumed that individuals with learning disabilities were incapable of grieving (Kitching, 1987, Read & Elliott, 2003). In more recent years, however, research has been conducted

suggesting that they do grieve and may respond in a similar manner to the general population (Harper & Wadsworth, 1993; Oswin, 1989). In addition to this, studies have also shown that individuals with learning disabilities may be more vulnerable to developing complications in the grieving process (Day, 1985; Emerson, 1977; Oswin, 1985).

Historically, this client group were not informed of a death, not offered the choice of participating in bereavement rituals and discouraged from displaying emotional responses to grief (Emerson, 1977; Hollins & Esterhuyzen, 1997; Wadsworth & Harper, 1991). On occasion, this was possibly due to well intentioned carers who wanted to protect the individual from any pain and suffering. The implications of this can, however, be far more devastating for the individual. As a result of this, there is a tremendous need for those who provide support to possess adequate knowledge of bereavement and the grieving process, which can assist them in offering appropriate and effective support at these times. One method of increasing knowledge and understanding is through the provision of training programmes for staff, although this is an area of limited research in relation to bereavement and individuals with learning disabilities.

1.6 AIMS

The aim of the current thesis is to develop a training course and investigate its impact on the knowledge of staff who currently work with individuals with learning disabilities about bereavement and grief, in general and in relation to individuals with

learning disabilities, and regarding support that can be offered at a time of bereavement.

A further aim is to assess the impact the training course has on staff members self rated levels of confidence about supporting an individual with a learning disability who has experienced bereavement.

1.7 HYPOTHESES

The following hypotheses are proposed:

1. There will be a significant difference in overall knowledge of bereavement and grief between group one (after receiving training) and group two (prior to receiving training). It is also predicted that training will have a significant impact on overall knowledge of bereavement and grief for both groups.

2. There will be a significant increase in participants' knowledge after training:
    a. Participants' knowledge about bereavement and grief will improve after training
    b. Participants' knowledge about bereavement and grief in individuals with learning disabilities will improve after training
    c. Participants' knowledge about supporting an individual with a learning disability at a time of bereavement will improve after training

d. Participants' overall knowledge, as measured by total scores, about bereavement and grief will improve after training.

3. This knowledge increase will be sustained over time as evidenced by the one month follow-up.

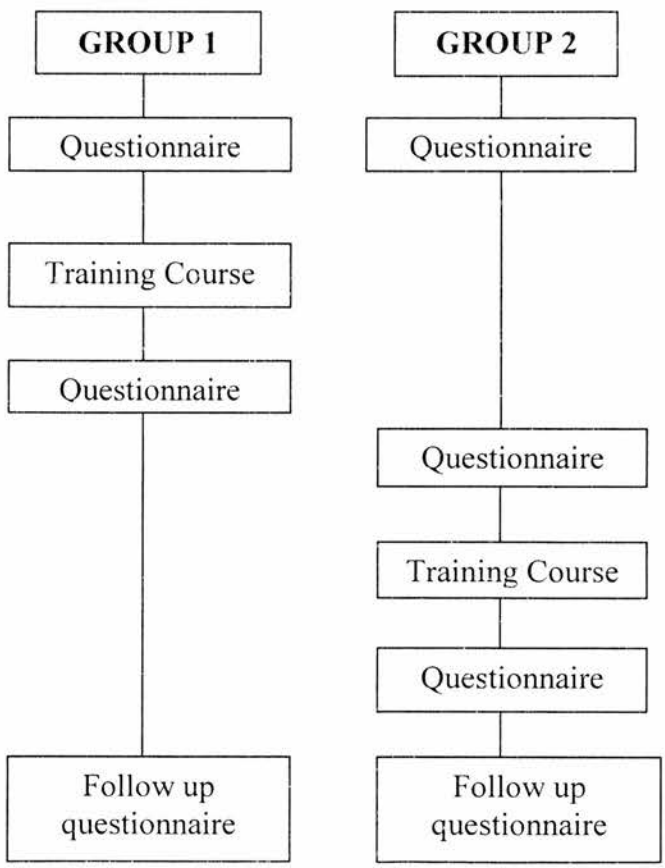
4. Participants' self rated levels of confidence about supporting individuals with a learning disability who have experienced bereavement will improve after training and be sustained over time, as evidence by the one month follow-up.

CHAPTER 2 : METHOD

2.1 DESIGN

A mixed design was used, incorporating both between and within participant comparisons to investigate the impact of staff training on knowledge about bereavement and grief, in general and in relation to individuals with learning disabilities, and of support that can be offered at these times. Two groups of participants were recruited with the training course being offered to both groups but at different times, as displayed in the diagram below.

Figure 1: Study design



The independent variable in the current study is the training course. The dependant variable is the scores obtained on the questionnaire.

2.2 POWER ANALYSIS

There is limited research focusing on support staffs' knowledge and confidence in relation to bereavement and grief in individuals with a learning disability in order to identify a likely effect size. Previous research has, however, been conducted on staff training and its impact on knowledge of challenging behaviour, in which a large effect size was found (McKenzie et al., 2000). In order to calculate an effect size for tests of difference, Clark-Carter's (2004) formula was utilised. Based on an estimate of sample size (setting power at 0.8 and alpha level at 0.05), one tailed between participants tests of difference would require a minimum of twenty in each group, and within participants tests of difference would require a minimum of twelve participants in each group, for a large effect size to be obtained. The final study had a total of forty eight participants with twenty four in each group.

2.3 PARTICIPANTS

The two groups in the study consisted of support workers, team leaders and care coordinators. All participants were recruited from support provider organisations within the researcher's health board area and provided direct input to individuals with learning disabilities on a regular basis. Initially, seventy participants were identified, with thirty five being randomly allocated to each group. Due to staff sickness and participants being required to cover shifts, the final number of

participants was forty eight, with twenty four participants in each group (69% of those initially recruited).

2.4 ETHICS

2.4.1 Ethical Approval

Prior to beginning the research project, the local ethics committee was contacted. A letter was received indicating that it was not necessary to submit a full ethical application as the study was being conducted with a non clinical population (Appendix 1). This was also confirmed by the University Research Ethics Tutor.

2.4.2 Ethical Considerations

The ethical implications of the study were considered prior to designing and commencing the research. It is recognised that bereavement can be a difficult and distressing subject for many individuals. It was, therefore, acknowledged that some individuals may not wish to participate. Participation in the study was on a voluntary basis and each participant was asked to complete a consent form at the beginning of the study (Appendix 2). Participants were informed that all responses and information gathered would be treated in confidence and that they could withdraw from the study at any time. It was acknowledged at the beginning of the research that a certain degree of distress may result due to the emotive nature of the topic being discussed and at the end of the training course, participants were provided with a list of contact details for organisations that could offer support, should it be required.

There was concern about the ethical implications of including a control group in the study where no training was offered. It was, therefore, decided that as opposed to recruiting a control group who would not receive training, it would be beneficial to recruit a second group but offer the training at a later date to allow comparisons to be made between receiving the training and not receiving training.

2.5. RECRUITMENT

Initially, a letter was sent to the managers of twenty four support provider organisations within the researcher's health board area (Appendix 3). This letter provided details of the research and asked if staff within their organisation would consider participating in the study. The letter clearly explained that the training would be offered for free and, in return, participants would be required to fill out questionnaires at three or four different time points dependant on which group they were allocated to. Those participants in group one would be required to complete the questionnaire (Appendix 5) on three separate occasions; immediately before the training, immediately after receiving the training and at a follow up, approximately one month after completion of the training. Those participants in group two would be required to complete the questionnaire on four separate occasions; one week before the training, immediately prior to receiving the training, immediately after receiving the training and at a follow up approximately one month after completion of the training. If they were interested in participating, the managers were asked to pass on information of the research, including its purpose and outline, to their members of staff in order to ascertain the number of individuals interested. Organisations were contacted by telephone and e-mail approximately two weeks

after the initial letter was sent to clarify the exact number of individuals interested in participating. Managers and their members of staff were also encouraged to contact the researcher if they had any questions about the study.

2.5.1 Response Rate

Responses were initially received from fourteen organisations who indicated an interest in participating in the study, reflecting a response rate of 58%. Of the twenty four services approached, no response was received from ten of the organisations. Of those who expressed an initial interest in participating, eight organisations took part in the final study. Six organisations that initially expressed interest contacted the researcher indicating that they were unable to free up staff, therefore, they withdrew from the study.

2.6 PROCEDURE

Participants were randomly allocated to group one or two. On arrival at the training event, all participants were asked to sign a registration form to monitor attendance. The participants in group one were asked to complete the consent form (Appendix 2) and questionnaire (Appendix 5) immediately prior to receiving the training and return them to the researcher. Participants in group two were also asked to complete the consent form and questionnaire at this time, a week before attending the training. These were distributed by e-mail to the service managers of each organisation, to be circulated to the participants. All twenty four questionnaires were received from the participants in group two a week before the training was scheduled to take place. Participants were assured that questionnaires sent by e-mail would be printed and the

e-mail immediately deleted to ensure anonymity. On completion of the training course, group one were asked to complete the questionnaire again. At the second training session, group two were asked to complete the questionnaire again immediately prior to receiving the training and on completion of the training. Both groups were then asked to complete the questionnaire at a one month follow up. Each questionnaire took an average of ten minutes to complete.

2.6.1 Organisation of the Training Course

When recruitment was complete, two training days were organised. All facilities and equipment were organised by the researcher and a community centre within the researcher's health board area was contacted to arrange a room for both training days. The training was scheduled between 10:00am and 4:00pm, which included all breaks and time to complete the questionnaires.

2.6.2 Development of the Training Course

There was no existing training course found that focused on bereavement in individuals with learning disabilities. In order to improve staffs' knowledge and understanding of bereavement and grief in individuals with a learning disability, a one day training course was developed by the researcher. All information contained within the training was based on the literature and evidence base focusing on bereavement and grief. The training course provided information on bereavement and grief, in general and in relation to individuals with learning disabilities, and of supporting an individual with a learning disability through bereavement. The two

training events, which ran a week apart, were run solely by the researcher and the same training package was used for each event.

The staff training included information in the following areas:

- *Bereavement and Grief*
    - What is bereavement and why do we grieve
    - Theories and models of grief
    - Tasks of grieving
    - Grief responses
    - Risk factors in bereavement outcome
    - Complicated grief
- *Bereavement and Learning Disability*
    - What can make bereavement more difficult for individuals with learning disabilities
    - Grief reactions and responses in individuals with learning disabilities
    - Factors increasing vulnerability of developing complicated grief reactions
- *Supporting an Individual with a Learning Disability through Bereavement*
    - Preparation for bereavement
    - Practical support after bereavement
    - Facilitating the grieving process
    - Identifying difficulties
    - Looking after yourself
    - Available resources

The training also included a number of activities as recommended by Goodall et al. (1994) in order to increase participation and promote discussion. All participants engaged well with the activities.

The first block of training on bereavement and grief was delivered over the first hour, after which participants were given a fifteen minute break. The second block of training on bereavement and learning disability was delivered over an hour and a half before breaking for lunch. The remainder of the day was spent on a case study followed by a group discussion and training on supporting an individual with a learning disability at a time of bereavement, which took approximately an hour and a half. At the end of the training, time was allocated to ask questions, although questions and comments were also encouraged throughout the training.

There was an additional section at the end of the post-training questionnaire in which participants were asked to comment on the training course itself and give feedback on its relevance to them, usefulness and applicability.

2.6.3 Follow-up Data Collection

In order to identify if improvements in knowledge were maintained after a specific period of time had elapsed, letters (Appendix 4) and questionnaires (Appendix 5) were sent out to each participant approximately four weeks after completion of the training course. Forty eight questionnaires were sent out and fifteen were returned, indicating a 31.3% response rate.

2.7 MEASURES

One measure was used in the current study to investigate the impact of staff training on each of the areas outlined in the aims. There was no existing measure found to assess staff knowledge about bereavement and grief, in general and in relation to individuals with learning disabilities, and of support that can be offered at a time of bereavement. A measure, therefore, had to be developed by the researcher for use in the current study (Appendix 5). There are diagrams available on the methodical process of designing a questionnaire (e.g. StatPac Inc, 2003), which were used to inform the development of the questionnaire.

2.7.1 Design of the Questionnaire

Each questionnaire had a cover sheet asking for demographic information. This included age, gender, position within the organisation for which they currently work and length of time they had worked with individuals with learning disabilities. Participants were asked to include the last four digits of their phone number on the questionnaire so individual forms could be matched and allow for within and between group comparisons to be made.

Four general questions were also asked about their experience of working with a bereaved individual with a learning disability, whether they have access to bereavement guidelines in their organisation and whether they had previously received training on bereavement. A final question asked participants to rate on a scale their degree of confidence about supporting an individual with a learning disability who has experienced bereavement.

A total of ten questions were developed utilising an open ended approach. For each question, a list of pre-coded response categories were identified based on the literature and evidence base. The aim of this was to allow categorisation of responses and to assist in scoring the questionnaires. When initially constructing the questionnaire, several response options were considered. An open ended question format was chosen as this has been found to be a useful method for testing hypotheses about general awareness and ideas (Vinten, 1995). It was also considered that this would reduce the risk of biasing responses and would allow for a more detailed analysis of answers. A simple yes/no format would possibly lack sensitivity to changes in knowledge over the time period, along with potential problems of acquiescence.

2.7.2 Piloting the Questionnaire

The pilot questionnaire was distributed to five professionals with experience and knowledge of bereavement and learning disability. These professionals were asked to comment on the content of the questionnaire and recommend any suggestions for improvement. Of the five professionals consulted, three made comments about possible amendments. This was purely concerned with the wording of three of the questions, which were considered to be slightly unclear and possibly too complex.

A further five questionnaires were distributed to support providers (10% of the total participant sample). These were completed by individuals who did not participate in the final study. These individuals were asked to complete the questionnaire and

evaluate readability and clarity of questions, time required to complete the questionnaire and make suggestions for revisions. Each questionnaire was completed appropriately and one support worker made a suggestion about a possible amendment. The staff member commented on whether examples could be included for each question to assist the participants in responding. The questionnaire was designed using open questions in order to obtain information that represented the participants' current knowledge. On the basis of this and in order not to compromise the validity of the questionnaire, it was decided not to include examples, which may influence participants' responses and misrepresent their underlying knowledge.

All recommended changes were considered to be relatively minor. The main aim of the questionnaire is to extract accurate and detailed information about participants' knowledge of the subject area and this was not disputed in the pilot study. The pilot study indicated that the questionnaire had face, social and content validity.

2.7.3 Design of the Scoring Criteria

The first section of the questionnaire was designed to extract information for the purpose of descriptive results. The remainder of the questionnaire was designed to gain information on the specific knowledge of staff in relation to the three areas covered in the training course. For each question, a list of predetermined response categories were identified with detailed examples included for each category. Participants were required to make reference to each category and give an appropriate example in order to score a point. The total number of points for each question varied depending on the number of categories listed.

2.7.3.1 Knowledge of Bereavement and Grief

Within this section, participants were asked to answer four general questions about bereavement and grief. The first question asked participants to explain the tasks of grieving as identified by Worden (2003). This model was utilised due to its previous applicability for individuals with learning disabilities in helping to understand the grieving process and its use in grief work (Bennett, 2003; Elliott, 1995; Luchterhand & Murphy, 1998; Read, 2003, 2007; Read et al., 1999). While other phase and stage models are equally useful, it was considered that due to the wide variability in terms used, it would prove more difficult to categorise the potentially wider range of responses.

The second question asked participants to describe some of the grieving responses associated with 'normal grieving'. The literature clearly outlines a wide range of grief responses which are often categorised into four areas; physical, emotional/affective, behavioural and cognitive (Read, 2003, 2007; Schuchter & Zisook, 1993; Simos, 1979).

The third question asked participants to comment on their understanding of the term 'complicated grief'. It is recognised that certain types of losses may overwhelm an individual's ability to accept, cope and move on, leaving them stuck in grief or unable to grieve (Horowitz et al., 1980). The term complicated grief is commonly used in the literature to describe grief that is more intense and lasts longer than normal grieving (Kim & Jacobs, 1991; Middleton et al., 1993; Parkes, 1996;

Worden, 2003). Complicated grief can also manifest itself in many forms, with subtypes having been suggested including delayed (Parkes, 1965), chronic, (Worden, 2003) and unresolved (Zisook & Lyons, 1991).

The fourth question asked participants to describe factors that can influence an individual's response and reaction to bereavement. The literature describes many factors that can help to understand individual reactions to bereavement and potentially impact on bereavement outcome (Raphael, 1984; Schuchter & Zisook, 1993; Worden, 2003). These include the relationship with the deceased, circumstances surrounding the death, additional stresses, social support and the personality traits and previous loss experiences of the bereaved individual.

Table 1 details the response categories for one of the questions, with a description of each category and examples of responses. Table 2 (Appendix 6) outlines the description of response categories with examples for the other questions in section one of the questionnaire.

Table 1: An example of the Response Categories for a Bereavement and Grief Question

	RESPONSE CATEGORY	***DESCRIPTION***	***EXAMPLES***
QUESTION 2: PLEASE CAN YOU DESCRIBE SOME OF THE GRIEVING RESPONSES OFTEN ASSOCIATED WITH 'NORMAL GRIEVING'.	Emotional	An accurate example of emotional responses associated with normal grieving	Sadness, anger, guilt, shock, loneliness, yearning, relief, anxiety
	Behavioural	An accurate example of behavioural responses associated with normal grieving	Social withdrawal, searching for the deceased, restlessness/over activity, crying
	Physiological	An accurate example of physical responses associated with normal grieving	Hollow feeling in stomach, lack of energy, breathlessness, loss of appetite, sleep disturbance
	Cognitive	An accurate example of thoughts associated with normal grieving	Disbelief, confusion, preoccupation with the deceased, rumination, helplessness

2.7.3.2 Knowledge of Bereavement in Individuals with a Learning Disability

Within this section, participants were asked to answer three questions about bereavement and grief in relation to individuals with a learning disability. The first question asked participants to describe reasons why having a diagnosis of learning disability can potentially make grief more difficult. The literature outlines the importance of recognising that individuals with learning disabilities may grieve in

the same way as the general population (Oswin, 1991). Individuals with learning disabilities may, however, have difficulty grieving due to level of cognitive impairment (Bimh & Elliott, 1982), the presence of communication difficulties (Cathcart, 1991; Cochrane, 1995), difficulties with emotion recognition and expression (Reed & Clements, 1989) and additional diagnoses, for example Autistic Spectrum Disorder or dementia (Read & Elliott, 2003).

The second question in this section asked participants to describe ways in which grief might be displayed by an individual with a learning disability. Researchers have recognised that due to the presence of additional difficulties, such as those mentioned above, the response to a loss may be displayed through non verbal means (Cathcart, 1994a; Emerson, 1977; Hollins & Esterhuyzen, 1997). Research also indicates that bereavement can impact on the behaviour and mental health of individuals with learning disabilities (Bonell-Pascual et al., 1999; Dodd, Dowling et al., 2005; Emerson, 1977; Hollins & Esterhuyzen, 1997). Grief reactions may, therefore, be evident through changes in behaviour, deterioration in mental health and the display of non verbal grief responses.

The third question asked participants to consider support that may be offered to an individual with a learning disability at a time of bereavement and identify factors that could increase vulnerability to complicated grief reactions. The literature on bereavement and individuals with a learning disability highlights lack of preparation for a loss (Bowey & McLaughlin, 2005), lack of participation in rituals (Palazon, 1991), lack of social support (McLoughlin, 1986) and multiple losses (Kitching,

1987; McLoughlin, 1986), as important factors that can increase an individual's vulnerability to additional complications following bereavement.

Table 3 details the response categories for one of the questions, with a description of each category and examples of responses. Table 4 (Appendix 7) outlines the description of response categories with examples for the other questions in section two of the questionnaire.

Table 3: An example of the Response Categories for a Bereavement, Grief and Learning Disability Question

	RESPONSE CATEGORY	***DESCRIPTION***	***EXAMPLES***
QUESTION 6: ASIDE FROM THE RESPONSES TO GRIEF RECOGNISED WITHIN THE GENERAL POPULATION, HOW ELSE MIGHT GRIEF BE DISPLAYED IN SOMEONE WITH A LEARNING DISABILITY?	Behavioural	An accurate example of possible behavioural responses	Challenging behaviour, self injurious behaviour, withdrawal, irritability, uncharacteristic aggression
	Mental Health	An accurate example of possible mental health issues	Depression, anxiety, adjustment disorder
	Non Verbal	An accurate example of non verbal grief reactions	Clinginess, minor illness, reluctance to go out, changes in appetite, uncharacteristic incontinence

2.7.3.3 Knowledge of Supporting an Individual with a Learning Disability Through Bereavement

Within this section, participants were asked to answer three questions about support that could be offered to an individual with a learning disability at a time of bereavement. The first question asked participants to describe practical support that could be offered before and after a death. The literature highlights the importance of preparation for bereavement (Kauffman, 1994) and ensuring individuals are encouraged to participate in bereavement rituals (James, 1995; Oswin, 1991). In addition to this, a key component of offering effective support involves recognising when difficulties are present that may require specialist intervention (Blackman, 2003).

The second question in this section asked participants to identify potential clues that an individual may be presenting with a complicated grief reaction. Researchers have identified a number of indicators of complicated grief (Lazare, 1979; Rando, 1993), which can be vital for early identification of difficulties and prevention of further decline.

The third question asked participants to describe techniques and skills that could assist them in offering emotional support and facilitating the expression of grief. The benefits of counselling techniques, such as listening and empathy and creative strategies have been demonstrated for use with bereaved individuals with learning disabilities (Read, 2003, 2007).

Table 5 details the response categories for one of the questions, with a description of each category and examples of responses. Table 6 (Appendix 8) outlines the description of response categories with examples for the other questions in section three of the questionnaire.

Table 5: An example of the Response Categories for a question about Supporting an Individual with a Learning Disability Through Bereavement

	RESPONSE CATEGORY	***DESCRIPTION***	***EXAMPLES***
QUESTION 9: WHAT ARE SOME OF THE CLUES THAT SOMEONE MIGHT BE SUFFERING A 'COMPLICATED GRIEF REACTION'?	Verbal	An accurate example of verbal clues to complicated grief	Conversation on themes of loss, unable to speak of deceased without 'fresh grief'
	Situational	An accurate example of situational clues to complicated grief	Minor events trigger intense grief reactions, lasting problems in employment and social roles, reduced interest in own life
	Behavioural	An accurate example of behavioural difficulties indicative of complicated grief	Preserving environment of deceased, imitation of deceased, developing similar physical symptoms to the deceased
	Mental Health	An accurate example of mental health problems indicative of complicated grief	Illness or death phobia, history of subclinical depression, low self esteem

2.7.4. Final Questionnaire

2.7.4.1 Inter-Rater Reliability

In order to determine inter-rater reliability for the categories used to score the open ended questions, twenty five of the completed questionnaires (18.5% of the 135 questionnaires returned in total from the pre, post and follow up measures) were analysed by two raters. A Kappa value was obtained for each of the questions as a whole and for individual categories within questions. The Kappa values and corresponding levels of agreement according to Fleiss (1981) for each question and individual categories are shown in Table 8 in the results section and in Table 9 respectively (Appendix 10).

2.7.4.2 Test-Retest Reliability

In order to determine the test-retest reliability of the questionnaire, it was administered to the twenty four participants in group two one week before they attended the training course. Participants were then asked to complete the questionnaire a week later immediately prior to receiving the training. The correlation values and levels of consistency are shown in Table 10 in the results section.

CHAPTER 3: RESULTS

The first part of this section will outline how the data was prepared for analysis, followed by the validity and reliability results of the questionnaire. This section will then go on to provide demographic information about the participants in the study with the use of descriptive statistics. The second part of the results section details the testing of each of the study's hypotheses and respective results.

3.1 PREPARATION OF DATA FOR ANALYSIS

Prior to analysis, the distribution of the variables was investigated by examining the skewness and kurtosis scores for each variable. All variables used in the analysis were normally distributed (Table 7, Appendix 9).

Analysis of the data was conducted using parametric tests with SPSS (Statistical Package for the Social Sciences) Version 14. The use of parametric tests is recommended when the data shows no obvious contraindications, such as skewness or marked display of variances (Kinnear & Gray, 2000). Parametric tests are also considered to be more powerful (Dancey and Reidy, 2004), robust and less likely to commit Type II errors (Clark-Carter, 2004). The use of parametric tests was deemed appropriate and, therefore, were used to analyse differences in mean scores across time.

The significance levels of test results, unless otherwise stated was set at $p = 0.05$.

3.2 VALIDITY AND RELIABILITY OF THE QUESTIONNAIRE

The face, social and content validity of the questionnaire was discussed within section 2.7.2 of the methodology. The next section will discuss the results of inter-rater reliability and test re-test reliability of the questionnaire. Convergent validity and criterion related validity could not be assessed as no existing measure was found to allow comparisons to be made.

3.2.1 Results of Inter-Rater Reliability

An overall Kappa score was obtained for each of the questions as a whole and a Kappa score obtained for individual response categories. The Kappa values and corresponding levels of agreement for each question assessed for inter-rater reliability are shown in Table 8. (See Table 9, Appendix 10 for the Kappa values and levels of agreement for individual response categories within each question).

Table 8: Inter-Rater Reliability for Complete Questions and Corresponding Categories used in the Analysis of Participants' Answers

QUESTION NUMBER	QUESTION	SIGNIFICANCE OF KAPPA (KAPPA VALUE AND P VALUE)	LEVELS OF AGREEMENT ACCORDING TO FLEISS (1981)
1	What are the 'tasks of grieving'?	K = 1.00 P < 0.001	Excellent
2	Please can you describe some of the grieving responses often associated with 'normal grieving'?	K = 1.00 P < 0.001	Excellent
3	What is your understanding of the term 'complicated grief'?	K = 0.95 P < 0.001	Excellent
4	What factors can influence a person's response and reaction to bereavement?	K = 0.95 P < 0.001	Excellent
5	What is it about having a learning disability that can make grief more difficult?	K = 0.94 P < 0.001	Excellent
6	Aside from the responses to grief recognised within the general population, how else might grief be displayed in someone with a learning disability?	K = 1.00 P < 0.001	Excellent
7	When offering support at a time of bereavement, what things can increase the likelihood of someone with a learning disability developing a complicated grief reaction?	K = 0.94 P < 0.001	Excellent
8	What practical support can you offer to assist someone with a learning disability before and after a death?	K = 1.00 P < 0.001	Excellent
9	What are some of the clues that someone might be suffering a 'complicated grief reaction'?	K = 1.00 P < 0.001	Excellent
10	When providing emotional support to someone with a learning disability, what techniques/skills can you use to help them express their grief?	K = 1.00 P < 0.001	Excellent

3.2.2 Results of Test-Retest Reliability

Pearson's Product Moment Correlation was utilised to assess the test-retest reliability of the questionnaire. The levels of consistency for each of the three sections and total scores are shown in Table 10.

Table 10: Test-Retest Reliability for Sections 1 to 3 and Total Scores

SECTION NUMBER	SECTION CONTENT	SIGNIFICANCE OF CORRELATION (R VALUE AND P VALUE)	STRENGTH OF THE CORRELATION COEFFICIENT
1	Bereavement and Grief	r = 0.98 p = <0.001	Strong
2	Bereavement, Grief and Individuals with Learning Disabilities	r = 0.85 p = <0.001	Strong
3	Supporting an Individual with a Learning Disability Through Bereavement	r = 0.82 p = <0.001	Strong
	Total Score	r = 0.94 p = <0.001	Strong

3.3 DESCRIPTIVE STATISTICS

The age of the participants within the study ranged from 22 to 61 (Mean = 38.96, SD = 11.19). A total of 39 females and 9 males participated. Of the 48 participants, 36 (75%) were support workers, 8 (16.7%) were care coordinators and 4 (8.3%) were team leaders. All participants currently worked within organisations providing support to individuals with learning disabilities and the number of years working

within the service ranged from 1 to 30 (Mean = 7.46, SD = 7.77). None of the participants had received training specifically on bereavement and individuals with learning disabilities, although 5 (10.4%) participants had received prior training on bereavement (e.g. general bereavement training, preparing for bereavement). The remainder (89.6%) had received no prior training. Thirty two (66.7%) participants had access to bereavement guidelines in their organisation and 29 (60.4%) had previous experience of offering support to a bereaved individual with a learning disability.

3.4 HYPOTHESIS TESTING

Each hypothesis was tested using inferential statistics. Independent samples t-tests, Paired Samples t-tests, One Way Analysis of Variance and a Mixed ANOVA were used to analyse the data and investigate hypotheses 1 to 4. The significant results for each hypothesis are reported below.

3.4.1 Hypothesis 1

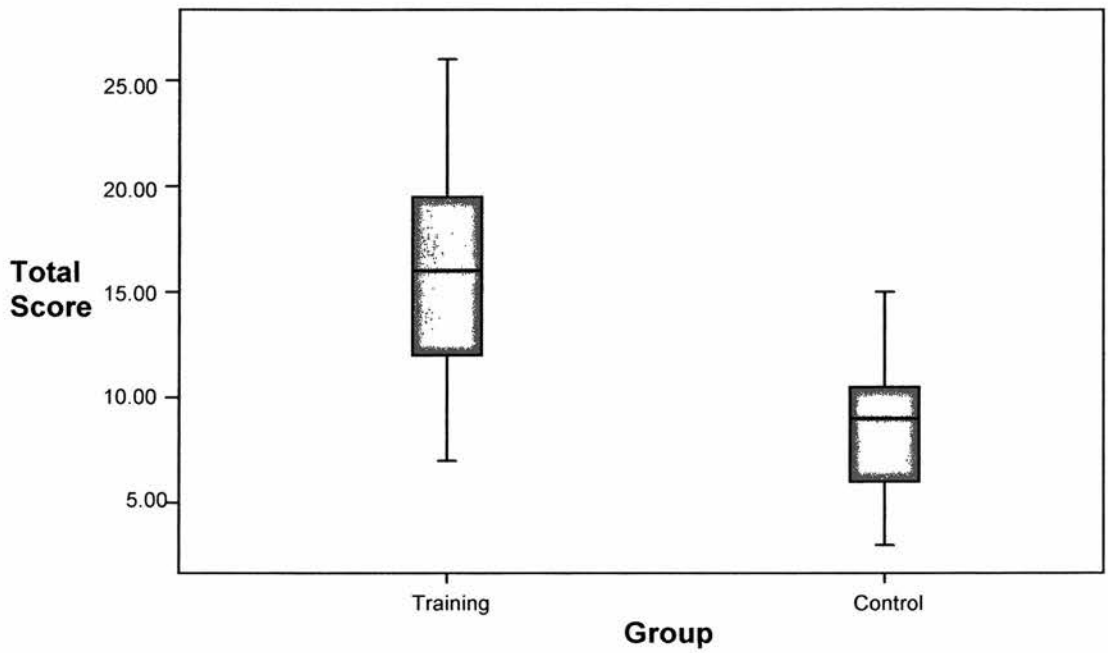
There will be a significant difference in overall knowledge between group one (after receiving training) and group two (prior to receiving the training). It is also predicted that training will have a significant impact on overall knowledge of bereavement and grief for both groups.

One Way Analysis of Variance was used to identify any differences between group 1 (after training) and group 2 (before training). Results showed that there was no significant difference between the baseline measures of the two groups with regards

to total score ($F = 1.11$, $df = 1$, $p = 0.298$). One Way Analysis of Variance also revealed no significant differences between the two groups on section one ($F = 2.315$, $df = 1$, $p = 0.135$), section two ($F = 0.834$, $df = 1$, $p = 0.366$) and section three ($F = 0.416$, $df = 1$, $p = 0.522$) of the questionnaire, prior to training.

One Way Analysis of Variance revealed no significant differences between the two groups on section one ($F = 0.484$, $df = 1$, $p = 0.490$), section two ($F = 2.74$, $df = 1$, $p = 0.105$) and section three ($F = 0.266$, $df = 1$, $p = 0.609$) of the questionnaire, after training. One way analysis of variance of total scores suggests that there were significant differences between participants who had received the training (group 1) and those who had not yet received the training (group 2) ($F = 39.49$, $df = 1$, $p = <0.001$). Participants who had received the training achieved significantly higher total scores on the questionnaire (Mean = 16.08, SD = 4.87) than the participants in group 2 (pre-training) (Mean = 8.50, SD = 3.35) (See Figure 2).

Figure 2: Comparison of the Two Participant Groups in Terms of Total Scores on the Questionnaire



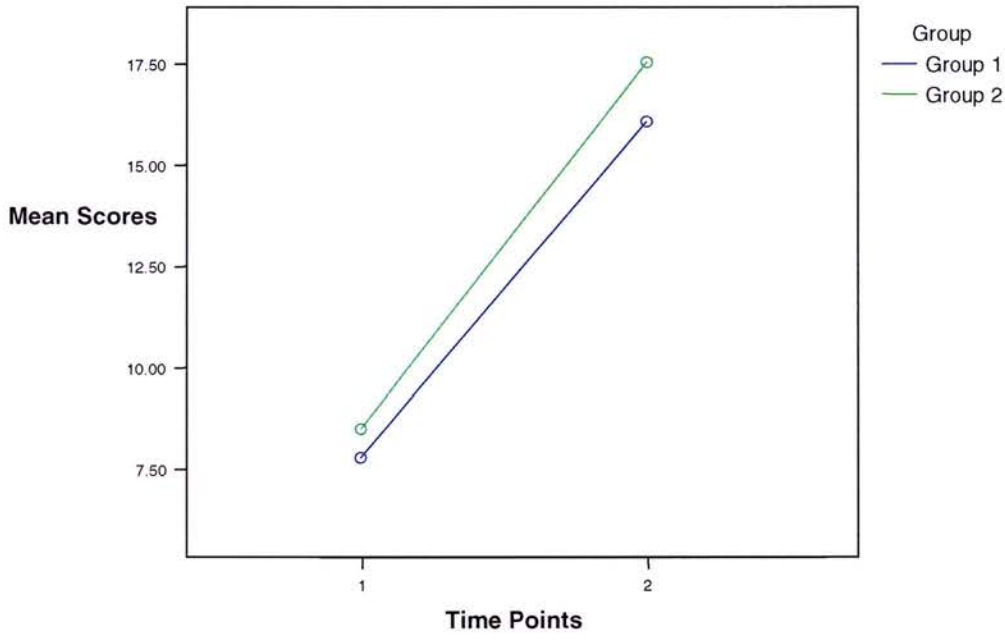
This information shows that there was a significant difference between the scores obtained by participants in group 2 (post training) and the scores obtained by participants in group 1 (pre-training).

A 2 x 2 (group by time) Mixed ANOVA with repeated measures was then used in order to compare the mean overall scores of group one and group two both before and after training. This analysis was utilised to examine the main effects of group and time and any interaction of the two variables. Analysis showed that the main effect for group was not significant ($f = 1.18$, $df = 1$, $p = 0.284$), indicating that the effect of training was not dependent on group. Results also showed a significant

main effect for time (f = 101.25, df = 1, p = <0.001), indicating that training had a significant impact on mean overall scores in both groups of participants, as predicted.

Results also showed that there was no significant interaction between the variables of group and time (f = 0.19, df = 1, p = 0.665). This is displayed in Figure 3.

Figure 3: Mean Estimates of Scores Pre and Post Training for Groups 1 and 2



The means and standard deviations for both groups, pre and post training are shown in Table 11.

Table 11: Means and Standard Deviations for Overall Scores of Group 1 and Group 2 Pre and Post Training

GROUP	TIME POINT	NUMBER	MEAN	STANDARD DEVIATION
Group 1	Pre-training	24	7.79	4.12
	Post-training	24	16.08	4.87
Group 2	Pre-training	24	8.50	3.35
	Post-training	24	17.54	5.62

These results show that there was a significant difference in the scores obtained by participants in both groups before and after training.

Summary of Hypothesis One

The findings of hypothesis one demonstrate that there was a significant difference in overall knowledge between the group that received the training and the group that had not yet received the training. This is shown by:

- The significant difference between the total scores of the group that received the training (group 1) and the group that had not received the training (group 2), despite there being no difference in total scores and subsection scores between the two groups at baseline (prior to either group receiving training).

The results also demonstrate that training had a significant impact on overall knowledge in both groups. This is shown by:

- The significant main effect of time, indicating that training had a significant impact on mean overall scores in both groups of participants. The effect of training was not found to be dependant on group and there was no significant interaction between the variables of group and time.

On the basis of the above findings hypothesis one was accepted.

Due to the lack of significant differences between the two groups, the groups were combined and all further analyses were conducted using within participant comparisons.

3.4.2 Hypothesis 2

There will be a significant increase in participants' knowledge after training.

Hypothesis 2 was investigated on four levels;

a. Whether participants' knowledge about bereavement and grief improved after training.
b. Whether participants' knowledge about bereavement and grief in individuals with learning disabilities improved after training.
c. Whether participants' knowledge about supporting an individual with a learning disability at a time of bereavement improved after training.
d. Whether participants' overall knowledge, as measured by total scores, about bereavement and grief improved after training.

Hypothesis 2: part a

Participants' knowledge about bereavement and grief will improve after training.

One-tailed Paired Samples t-tests were used in order to compare participants' knowledge of bereavement and grief pre and post-training (i.e., scores on section 1 of the questionnaire). The variable representing the total number of response categories for general knowledge about bereavement and grief that participants' correctly identified was used in the analysis. Results showed a significant difference between participants' knowledge about bereavement and grief prior to training and immediately after training ($t = -13.99$, $df = 47$, $p = <0.001$) and prior to training and at follow-up ($t = -6.25$, $df = 14$, $p = <0.001$). The means and standard deviations for each of these pairings are shown in Table 12.

Table 12: Means and Standard Deviations for General Knowledge about Bereavement and Grief According to Time Pairings

TIME POINTS	NUMBER	MEAN	STANDARD DEVIATION
Pre-training	48	3.21	1.92
Post-training	48	7.85	2.68
Pre-training	48	3.21	1.92
Follow-up	15	7.67	3.09

These results show that participants' knowledge about bereavement and grief improved significantly after training.

Hypothesis 2: part b

Participants' knowledge about bereavement and grief in individuals with a learning disability will improve after training.

One-tailed Paired Samples t-tests were conducted in order to compare participants' knowledge of bereavement and grief in individuals with learning disabilities pre-training and post-training (i.e., scores on section 2 of the questionnaire). The variable representing the total number of response categories for knowledge about bereavement and grief and individuals with learning disabilities that participants' correctly identified was used in the analysis. Results showed a significant difference between participants' knowledge of bereavement and grief in relation to individuals with learning disabilities prior to and immediately after training ($t = -8.87$, $df = 47$, $p = <0.001$) and prior to training and at follow-up ($t = -9.35$, $df = 14$, $p = <0.001$). The means and standard deviations for each of these pairings are shown in Table 13.

Table 13: Means and Standard Deviations for Knowledge about Bereavement and Grief in Individuals with a Learning Disability According to Time Pairings

TIME POINTS	NUMBER	MEAN	STANDARD DEVIATION
Pre-training	48	2.19	1.10
Post-training	48	4.40	1.87
Pre-training	48	2.19	1.10
Follow-up	15	5.33	1.23

These results show that participants' knowledge about bereavement and grief in individuals with a learning disability improved significantly after training.

Hypothesis 2: part c

Participants' knowledge about supporting an individual with a learning disability through bereavement will improve after training.

One-tailed Paired Sample t-tests were conducted in order to determine if participants' knowledge of supporting an individual with a learning disability through bereavement improved after training (i.e., scores on section 3 of the questionnaire). The variable representing the total number of response categories for knowledge about supporting an individual with a learning disability through bereavement that participants' correctly identified was used in the analysis. Results showed a significant difference between participants' knowledge prior to and immediately after training ($t = -9.86$, $df = 47$, $p = <0.001$) and prior to training and at follow-up ($t = -4.92$, $df = 14$, $p = <0.001$). The means and standard deviations for each of these pairings are shown in Table 14.

Table 14: Means and Standard Deviations for Knowledge about Supporting an Individual with a Learning Disability Through Bereavement According to Time Pairings

TIME POINTS	NUMBER	MEAN	STANDARD DEVIATION
Pre-training	48	1.92	1.33
Post-training	48	4.33	1.67
Pre-training	48	1.92	1.33
Follow-up	15	4.87	2.13

These results show that participants' knowledge about supporting an individual with a learning disability at a time of bereavement improved significantly after training.

Hypothesis 2: part d

Participants' overall knowledge about bereavement and grief will improve after training

One-tailed Paired Samples t-tests were used in order to compare participants' overall knowledge of bereavement and grief pre and post-training (i.e., total scores on the questionnaire). The variable representing the total number of defining criteria for overall knowledge about bereavement and grief that participants' correctly identified was used in the analysis. The potential scores on the questionnaire ranged between 0-34.

Results showed a significant difference between participants' overall knowledge about bereavement and grief prior to training and immediately after training ($t = -14.63$, $df = 47$, $p = <0.001$) and prior to training and at follow-up ($t = -9.43$, $df = 14$, $p = <0.001$). The means and standard deviations for each of these pairings are shown in Table 15.

Table 15: Means and Standard Deviations for Overall Knowledge about Bereavement and Grief According to Time Pairings

TIME POINTS	NUMBER	MEAN	STANDARD DEVIATION
Pre-training	48	7.42	3.85
Post-training	48	16.71	5.28
Pre-training	48	7.42	3.85
Follow-up	15	17.87	5.85

These results show that participants' overall knowledge about bereavement and grief improved significantly after training.

In order to further investigate participants' knowledge about the three areas measured, additional exploration of the data was conducted on the individual response categories. Table 16 shows the percentage of participants that correctly identified each of the response categories within the three sections of the questionnaire before and after training.

Table 16: Response Categories Identified Before and After Training with the Number and Percentages for Each Time Point

RESPONSE CATEGORY	PERCENTAGE (AND NUMBER) CORRECTLY IDENTIFIED AT EACH TIME POINT	
	Pre-Training (N=48)	Post Training (N=48)
SECTION 1		
Acceptance	20.8% (N=10)	79.2% (N=38)
Experience	10.4% (N=5)	68.8% (N=33)
Adjustment	8.3% (N=4)	77.1% (N=37)
Resolution	2.1% (N=1)	68.8% (N=33)
Physiological	18.8% (N=9)	37.7% (N=18)
Emotional	79.2% (N=38)	97.9% (N=47)
Behavioural	45.8% (N=22)	52.1% (N=25)
Cognitive	6.3% (N=3)	20.8% (N=10)
Duration	18.8% (N=9)	75% (N=36)
Intensity	0% (N=0)	47.9% (N=23)
Subtype	6.3% (N=3)	18.8% (N=9)
Intrapersonal	18.8% (N=9)	37.5% (N=18)
Interpersonal	52.1% (N=25)	54.2% (N=26)
Circumstances of Death	37.5% (N=18)	47.9% (N=23)
SECTION 2		
Communication	27.1% (N=13)	58.3% (N=28)
Intellectual Ability	68.8% (N=33)	91.7% (N=44)
Comorbidity	2.1% (N=1)	18.8% (N=9)
Behavioural	75% (N=36)	89.6% (N=43)
Mental Health	0% (N=0)	22.9% (N=11)
Non Verbal	8.3% (N=4)	43.8% (N=21)
Unpreparedness	4.2% (N=2)	35.4% (N=17)
Exclusion	10.4% (N=5)	29.2% (N=14)
Isolation	6.3% (N=3)	29.2% (N=14)
Other	16.7% (N=8)	27.1% (N=13)
SECTION 3		
Proactive	8.3% (N=4)	58.3% (N=28)
Reactive	10.4% (N=5)	68.8% (N=33)
Environmental	10.4% (N=5)	22.9% (N=11)
Situational	2.1% (N=1)	20.8% (N=10)
Behavioural	45.8% (N=22)	58.3% (N=28)
Mental health	18.8% (N=9)	33.3% (N=16)
Verbal	0% (N=0)	12.5% (N=16)
Facilitation	62.5% (N=30)	66.7% (N=32)
Communication	16.7% (N=8)	29.2% (N=14)
Creativity	18.8% (N=9)	58.3% (N=28)

The information in Table 16 shows the pattern of responses on the questionnaire pre and post training and demonstrates an increase in response categories identified by participants within each of the three sections after receiving training.

Summary of Hypothesis Two

The findings of hypothesis two show that participants' knowledge of bereavement and grief improved significantly after training. This is shown by:

1. The significant increase in participants' knowledge about bereavement and grief.
2. The significant increase in participants' knowledge about bereavement and grief in relation to individuals with a learning disability.
3. The significant increase in participants' knowledge about supporting an individual with a learning disability at a time of bereavement.
4. The significant increase in overall scores.
5. The increase in the number of response categories identified by participants after training in section one (50%), section two (70%) and section three (40%) of the questionnaire, with a total increase of 61.8%.

On the basis of the above findings hypothesis two was accepted.

3.4.3 Hypothesis 3

Knowledge increase will be sustained over time as evidenced by the one month follow-up.

Hypothesis 3 was investigated on four levels;

a. Whether participants' knowledge about bereavement and grief was maintained one month after training.
b. Whether participants' knowledge about bereavement and grief in individuals with learning disabilities was maintained one month after training.
c. Whether participants' knowledge about supporting an individual with a learning disability at a time of bereavement was maintained one month after training.
d. Whether participants' overall knowledge, as measured by total scores, about bereavement and grief was maintained one month after training.

Hypothesis 3: part a

Participants' knowledge about bereavement and grief will be maintained one month after training.

One-tailed Paired Samples t-tests were used in order to compare participants' knowledge of bereavement and grief post training to follow-up (i.e., scores on section 1 of the questionnaire). Results showed no significant difference between participants' knowledge immediately after training and at follow-up ($t = 0.86$, $df =$

14, p = 0.403). The means and standard deviations for the time points are shown in Table 17.

Hypothesis 3: part b

Participants' knowledge about bereavement and grief in individuals with learning disabilities will be maintained one month after training.

One-tailed Paired Samples t-tests were used in order to compare participants' knowledge of bereavement and grief in individuals with learning disabilities post-training to follow-up (i.e., scores on section 2 of the questionnaire). Results showed no significant difference between participants' knowledge after training and at follow-up (t = -1.85, df = 14, p = 0.086). The means and standard deviations for the time points are shown in Table 17.

Hypothesis 3: part c

Participants' knowledge about supporting a bereaved individual with a learning disability will be maintained one month after training.

One-tailed Paired Samples t-tests were conducted in order to compare participants' knowledge of supporting a bereaved individual with a learning disability after training to follow-up (i.e., scores on section 3 of the questionnaire). Results showed no significant difference between participants' knowledge after training and at follow-up (t = -0.16, df = 14, p = 0.879). The means and standard deviations for the time points are shown in Table 17.

Hypothesis 3: part d

Participants' overall knowledge about bereavement and grief will be maintained one month after training.

One-tailed Paired Samples t-tests were used in order to compare participants' overall knowledge of bereavement and grief post-training to follow-up (i.e., total scores on the questionnaire). Results showed no significant difference between participants' overall knowledge about bereavement and grief after training and at follow-up ($t = -0.13$, $df = 14$, $p = 0.896$). The means and standard deviations for each of these pairings are shown in Table 17.

Table 17: Means and Standard Deviations for Total Score and Sections 1 to 3 of the Questionnaire from Post Training to Follow-up

SECTION	TIME PAIRING	NUMBER	MEAN	STANDARD DEVIATION
1: Bereavement and Grief	Post-training	48	7.85	2.68
	Follow-up	15	7.67	3.09
2: Bereavement, Grief and Individuals with Learning Disabilities	Post-training	48	4.40	1.87
	Follow-up	15	5.33	1.23
3: Supporting a Bereaved Individual with a Learning Disability	Post-training	48	4.33	1.67
	Follow-up	15	4.87	2.13
Total Score	Post-training	48	16.71	5.28
	Follow-up	15	17.87	5.85

The information in Table 17 shows that there were no significant differences in total score and the scores for each section from post-training to follow-up, indicating that knowledge was sustained.

Summary of Hypothesis Three

The findings of hypothesis three show that participants' knowledge was sustained one month after completion of the training course. This is shown by:

1. The lack of significant change in knowledge about bereavement and grief from post training to follow-up.
2. The lack of significant change in knowledge about bereavement and grief in individuals with learning disabilities from post training to follow-up.
3. The lack of significant change in knowledge about supporting a bereaved individual with a learning disability post training to follow-up.
4. The lack of significant change in overall scores.

On the basis of the above findings hypothesis three was accepted.

3.4.4 Hypothesis 4

There will be a significant increase in participants' self rated levels of confidence about supporting individuals with a learning disability who have experienced bereavement after training.

Hypothesis 4 was investigated on three levels;

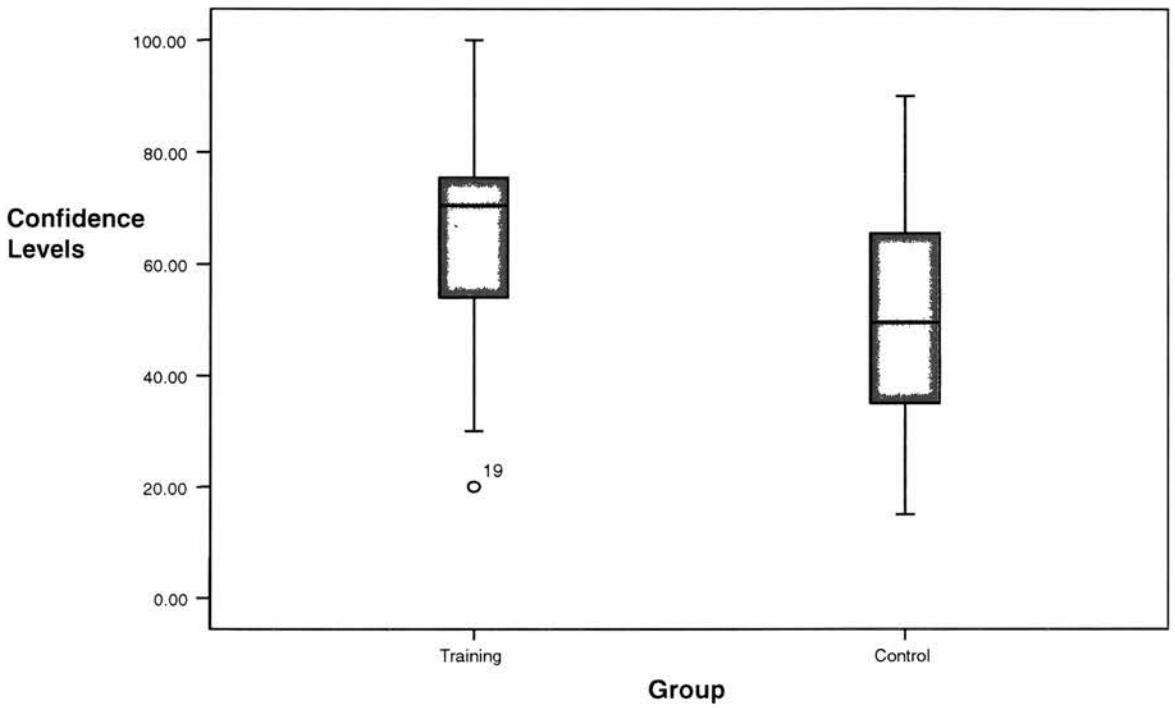
a. Whether there were any significant differences in self rated levels of confidence between participants' who had received training (group 1) and those who had not yet received training (group 2).
b. Whether participants' self rated levels of confidence improved after training.
c. Whether these confidence levels were maintained at a one month follow-up.

Hypothesis 4: part a

There will be a significant difference in self rated levels of confidence between group one (post-training) and group 2 (pre-training).

One-tailed Independent Samples t-tests revealed that there was no significant difference between the baseline measures of the two groups with regards to self rated levels of confidence ($t = 0.91$, $df = 46$, $p = 0.369$). Participants who had received the training (group 1) reported significantly higher confidence levels (Mean = 65.63, SD = 21.25) than the participants in the group 2 (pre-training) (Mean = 49.92, SD = 20.54) (See Figure 4). One-tailed Independent Samples t-tests revealed a significant difference in the self rated confidence levels of the participants who had received the training (group 1) and those who had not yet received the training (group 2) ($t = 2.60$, $df = 46$, $p = <0.05$).

Figure 4: Comparison of the Two Participant Groups in Terms of Self Rated Confidence Levels



Hypothesis 4: part b

Participants' self rated levels of confidence will improve after training.

One-tailed Paired Samples t-tests were conducted to compare participants' self rated levels of confidence in relation to supporting individuals with a learning disability who have suffered bereavement pre and post-training. Results showed a significant difference between participants' self rated confidence levels before and after training ($t = -9.52$, $df = 47$, $p = <0.001$) and prior to training and at follow-up ($t = -5.30$, $df = 14$, $p = <0.001$). The means and standard deviations for pre, post and follow up confidence levels are shown in Table 18.

Hypothesis 4: part c

Participants' self rated levels of confidence will be sustained at a one month follow-up.

One-tailed Paired Samples t-tests were conducted to compare participants' self rated levels of confidence in relation to supporting individuals with a learning disability who have suffered bereavement post training to follow-up. There was no significant difference between participants' self rated confidence levels post training to follow-up ($t = -1.66$, $df = 14$, $p = 0.119$). The means and standard deviations for before and after confidence levels are shown in Table 18.

Table 18: Means and Standard Deviations for Self Rated Confidence Levels Before and After Training

TIME POINT	NUMBER	MEAN	STANDARD DEVIATION
Pre-training	48	50.75	23.27
Post-training	48	70.56	21.61
Follow-up	15	71.27	11.14

The information in Table 18 shows that participants self rated levels of confidence improved after training and were maintained at a one month follow-up.

Summary of Hypothesis Four

The findings of hypothesis four show that participants' self rated levels of confidence improved after training and were maintained one month after completion of the training course. This is shown by:

1. The significant difference between the self rated levels of confidence between the group that had received the training (group 1) and the group that had not received the training (group 2).
2. The significant increase in self rated confidence levels after training.
3. The lack of significant change in confidence levels post training to follow-up.

On the basis of the above findings hypothesis four was accepted.

3.5 SUMMARY OF RESULTS

- Analysis provided preliminary support for the validity and reliability of the questionnaire used in the current study.
- There were significant differences in overall knowledge between the group that had received training (group 1) and the group that had not received training (group 2). Hypothesis 1 was, therefore, accepted.
- Results also showed that training had a significant impact on mean overall scores in both groups of participants. The effect of training was not found to be dependant on group and there was no significant interaction between group and time.
- Participants' knowledge of bereavement and grief, in general and in relation to individuals with a learning disability, and of supporting an individual with

a learning disability at a time of bereavement improved after training. Hypothesis 2 was, therefore, accepted.

- The results also showed an increase in the number of response categories identified by participants after training.
- Participants' knowledge was sustained one month after completion of the training course. Hypothesis 3 was, therefore, accepted.
- There were significant differences in self rated confidence levels between the group that had received training (group 1) and the group that had not received training (group 2). Participants' confidence about supporting an individual with a learning disability who has suffered bereavement increased significantly after training and was maintained at a one month follow-up. Hypothesis 4 was, therefore, accepted.

CHAPTER 4: DISCUSSION

This thesis investigated whether staff training improved participants' knowledge about bereavement and grief, in general and in relation to individuals with learning disabilities, and of supporting an individual with learning disability at a time of bereavement. This thesis also examined whether staff training improved participants' self rated levels of confidence about offering support to individuals with learning disabilities who have suffered bereavement. In addition to developing a training course for use in the study, a questionnaire was designed for the purpose of testing the related hypotheses.

The discussion will outline the results of the study in relation to the hypotheses and discuss each of these in turn. The methodological considerations of the study will then be discussed followed by the ethical and clinical implications of the research. Finally, suggestions for further research related to the study's findings will be explored, before the conclusions are outlined.

4.1 INTERPRETATION OF THE RESULTS

4.1.1 Significance of Receiving the Training (Hypothesis 1)

The results showed that there were significant differences in mean overall scores, as measured by the questionnaire, between the group that received the training (group one) and the group that had not yet received the training (group two). There were no significant differences between the baseline measures of the two groups and, therefore, these results suggest that receiving training significantly improved

knowledge. Further analysis of the data revealed a significant main effect of time, indicating that mean overall scores obtained after training, for both groups, were significantly higher than before training. There was no main effect of group, indicating that there was no significant differences between the two groups with regards to mean overall scores both before and after training. In addition to this, there was no significant interaction between group and time, indicating there was no differential response to training between the two groups. On the basis of these results, it can be concluded that receiving training significantly improved knowledge. Hypothesis one was, therefore, upheld.

Previous research has demonstrated that training has the capacity to improve knowledge and skills in staff members who work with individuals with learning disabilities (McKenzie et al., 2000; McKenzie et al., 2002). Within the literature on bereavement and grief in individuals with learning disabilities, many authors have highlighted the need for training to ensure staff possess adequate knowledge and are sufficiently prepared to offer support to an individual who has experienced bereavement (Cochrane, 1995; Kitching, 1987; Oswin, 1985). There is, however, limited research that has been conducted focusing specifically on the use of staff training to improve knowledge in relation to bereavement and learning disability.

4.1.2 Support Staffs' Knowledge of Bereavement and Grief (Hypothesis 2)

The results showed that participants' mean overall scores for knowledge about bereavement and grief were significantly higher immediately after training and this was maintained at a one month follow-up. The results also showed a significant

increase in participants' mean scores within each section of the questionnaire after training. Finally, the results showed an increase in the number of response categories identified by participants', overall and within each of the three sub-sections, before and after training. These results suggest that training significantly improved knowledge about bereavement and grief in all areas assessed and hypothesis two was, therefore, upheld. Each of the subsections will now be discussed in turn.

4.1.2.1 Overall Knowledge of Bereavement and Grief

The findings suggest that training significantly improved participants' overall knowledge about bereavement and grief. This was evidenced by the significant increase in mean total scores after training, compared with before training. As no previous research has been conducted on the outcome of training, specifically on staffs' knowledge of bereavement and grief, it is not possible to demonstrate consistency of findings. These results, however, clearly highlight the benefits of staff training and future research would be recommended to investigate this further.

The results showed that participants' knowledge at one month follow-up was significantly better than prior to training supporting previous findings, that training can improve knowledge in the longer term (Allen et al., 1997; McKenzie et al., 2000). There were no significant differences in participants' knowledge immediately after training to follow-up one month later, indicating that knowledge was maintained over time. Considering it has been stated that knowledge gained during staff training may be temporary and unlikely to be maintained over a longer time period (Cullen, 2000; Ziarnik & Bernstein, 1982), these preliminary results are

promising. Further research with a longer follow-up period would identify if knowledge continued to be sustained over a greater period of time.

The above significant results with regards to the follow-up data should, however, be interpreted with caution as the follow-up sample size was relatively small and lower than that required for statistical power. In addition to this, responder bias should be considered in the interpretation of the results. It is possible that the participants who responded at follow-up were those who had retained the relevant knowledge whereas those who did not respond had not. It could, therefore, be argued that the follow-up data may be unrepresentative of knowledge maintained one month after training. This limitation is discussed in greater detail later; however, these issues should be taken into account for all interpretations involving follow-up data.

4.1.2.2 Knowledge of Bereavement and Grief

Results showed that training significantly improved participants' general knowledge about bereavement and grief, as measured within section one of the questionnaire, compared with before training. In relation to questions one to three, prior to receiving the training, no participant was able to identify all of the response categories for each question and only one participant correctly identified all three response categories for question four. This suggests that participants' knowledge about bereavement and grief was limited before training.

Within section one of the questionnaire it is, however, perhaps not surprising that there were greater differences in the response categories identified before and after

training. In question one, participants were asked to describe the 'tasks of grieving'. This is a widely utilised framework in grief therapy and has been used to assist individuals with learning disabilities through the grieving process (Elliott, 1995; Luchterhand & Murphy, 1998; Read, 2003, 2007). The decision to include this model in the questionnaire was outlined in the method section, but it should be acknowledged that some models of grieving may be more widely recognised than others. It is also possible that knowledge of theoretical models is more relevant to skilled and trained professionals, for example counsellors, for whom it may have more clinical relevance. It could be argued that untrained members of staff may not be as familiar with this model and may not be expected to have such knowledge without additional training. This was evidenced within the current study as, prior to training, no participant was able to correctly identify all four response categories for the 'tasks of grieving'. Some participants did, however, identify concepts that would be found in other models of grieving, for example initial periods of shock, denial and yearning, which are common elements of stage models of grieving. It could be argued that participants gained knowledge of the 'tasks of grieving' after training, but this question did not take into account knowledge that participants may have possessed about alternative models of grieving. It may, therefore, have been beneficial to include a more general question about models of grieving, as opposed to asking a specific question based on one model.

Prior to training, no participant was able to identify all four categories for 'normal grief responses', but participants were more likely to include 'emotional' and 'behavioural' reactions in their answers. Previous research has found that, when

asked to identify common reactions to bereavement, staff more frequently recognise behavioural and emotional responses (Dodd, McEvoy et al., 2005; Murray et al, 2000), which supports the findings of the current study. The number of participants identifying the categories of 'emotional' and 'behavioural' also increased after training. The 'cognitive' and 'physiological' grief responses were, however, less likely to be identified by participants, both before and after training. This finding could be due to the fact that less time was spent discussing normal grief responses during the training course, in order to allow for more time to be spent discussing the learning disability and support sections. In addition to this, participants were asked to give examples of grief responses, which are extensive and wide ranging (Kim & Jacobs, 1991; Rando, 1993). It is possible, that as opposed to writing a long list of responses, participants' chose to list a smaller number of examples and concentrated on those more widely recognised that others.

The term 'complicated grief' was used within the current study to represent grief that does not follow the expected course. While complicated grief is a commonly used term in the literature (Blackman, 2003), definitions vary extensively. It is, therefore, possible that this term was not one that participants were familiar with prior to training. The number of participants identifying each category increased after training, but the 'duration' response category was more commonly identified, with seventy five per cent of participants including an appropriate example in their answers. No participant identified the 'intensity' category prior to training. After training, however, nearly half of the participants were able to identify this category in their answers, indicating an increase in knowledge. Complicated grief reactions are

characterised by the duration and intensity of the grieving process (Averill, 1968; Kim & Jacobs, 1991; Middleton et al., 1993; Parkes, 1996; Worden, 2003) and the ability of participants to identify these factors increased after training. After training, however, only nine participants identified the 'subtype' category. It has been stated that complicated grief is a more appropriate term to describe difficulties with the grieving process, as opposed to using subtypes (Prigerson & Maciejewski, 2006; Prigerson & Jacobs, 2007), which raises the question of whether this was a necessary inclusion as a response category. It could also be argued that support staff may not be required to possess this level of knowledge about specific types of complicated grieving.

Prior to receiving training, only one participant was able to identify all three categories related to factors that can influence an individual's reaction to bereavement. After training, while there was an increase in the response categories identified, 'intrapersonal' and 'circumstances of death' were still identified by less than half of the participants post training. There are a number of factors that may account for this, for example participants being able to draw on previous personal experience of bereavement. It could be argued that it would have been beneficial to include a question in the questionnaire asking about personal experiences of bereavement to allow any relationship between this and knowledge to be identified.

The literature and research about bereavement and grief in relation to individuals with learning disabilities, highlights the need for training that provides staff with information on the grieving process, normal and complicated grief reactions and

factors that can influence bereavement outcome (Conboy-Hill, 1992; Harper & Wadsworth, 1993; James, 1995; Kauffman, 1994; Read, 2003). This is considered to be very important as the knowledge and skills of staff are essential to ensure bereaved individuals with learning disabilities receive effective and appropriate support (Hastings, 1995; Rose, 1995). These findings clearly demonstrate increased knowledge about bereavement and grief, which could potentially have a positive impact on the services offered to clients at a time of bereavement.

4.1.2.3 Knowledge of Bereavement and Grief in Individuals with a Learning Disability

Results showed that training significantly improved participants' knowledge about bereavement and grief in individuals with a learning disability, as measured within section two of the questionnaire, compared with before training. No participant was able to identify all of the response categories for each question prior to training. This suggests staff possessed limited knowledge about bereavement and grief in individuals with learning disabilities before training. This contradicts the findings of previous research that has found the knowledge of staff about bereavement and the grieving process in individuals with a learning disability to be quite good (Dodd, McEvoy et al., 2005; Murray et al., 2000). The study by Murray et al. (2000) was conducted with health and social care staff and comparisons between the findings should be interpreted with caution as level of qualification and different employment experiences could account for this variation. Dodd, McEvoy et al. (2005) studied the knowledge of direct care staff working within service provider organisations in Ireland, but caution should be made with generalising the findings to staff that work

in other geographical areas. It could be argued that the limited knowledge of participants prior to training may indicate they are lacking the skills to recognise signs of grief within this client group and additional factors that can serve to complicate the grieving process.

The number of response categories identified by participants within section two of the questionnaire increased after training. When asked to identify reasons why having a learning disability could potentially make grieving more difficult, the most commonly identified category prior to training was 'intellectual ability'. Previous research has found that staff and carers often associate learning disability with an inability to understand the concept of death (McEvoy & Smith, 2005; Moddia & Cheung, 1995). Within the current study, no participant stated that, because an individual has a learning disability, they will automatically be unable to understand the concept of death, but recognised that limited understanding could impact on the response to bereavement. After training, more than half of the participants identified 'intellectual ability' and 'communication' in their responses, indicating that they were able to recognise the potential impact of communication difficulties and intellectual ability on the grieving process in individuals with a learning disability. The number of participants identifying 'comorbidity' in their responses increased from one, before training, to nine after training, indicating that many participants still did not include this category in their answers post training. The research highlights the importance of recognising factors that can serve to complicate the grieving process and, therefore, additional methods of improving knowledge about the impact of additional diagnoses on the grieving process may need to be identified.

Prior to training, seventy-five per cent of participants correctly identified 'behavioural' as a potential manifestation of grief in individuals with a learning disability, which increased to nearly ninety per cent post training. This supports previous findings, which have shown that behavioural reactions to bereavement in individuals with a learning disability are more commonly identified by staff (Dodd, McEvoy et al., 2005; Murray et al., 2000). Before training, no participant identified the 'mental health' category, and only four participants included 'non verbal' grief responses in their answers. After training, while the number of participants identifying all three categories increased, only eleven participants identified 'mental health' in their answers post training. Previous research has demonstrated that bereavement can impact on the behaviour and mental health of individuals with learning disabilities (Bonell-Pascual et al., 1999; Dodd, Dowling et al., 2005, Emerson, 1977, Hollins & Esterhuyzen, 1997). A substantial amount of time was spent discussing grief reactions in individuals with a learning disability during the training course and it is surprising that only eleven participants identified the 'mental health' category after training. In addition to this, after training, less than half of the participants included 'non verbal' grief responses in their answers. Within the literature, it is acknowledged that communication difficulties could lead to grief being expressed through non verbal means (Blackman, 2003; Cathcart, 1994a). Staffs' ability to recognise non verbal displays of grief is also considered important as this could reduce their client's vulnerability to developing behavioural and psychiatric difficulties (Matson & Sevin, 1994). It has been stated that staff require knowledge of grief responses in individuals with learning disabilities in order to

respond appropriately, recognise difficulties and avoid diagnostic overshadowing (Hollins & Esterhuyzen, 1997). It could, therefore, be argued that these issues require greater attention during training or the use of additional methods to improve knowledge.

There was an increase in the number of response categories identified after training, for elements of support that could potentially create difficulties for the bereaved individual with a learning disability. After training, however, less than half of the participants included each of the responses in the answers. After training, participants were more likely to identify 'unpreparedness', 'exclusion' and 'isolation' as elements of support that could potentially create additional difficulties for the bereaved individual with a learning disability. These findings support previous research, which has shown that staff identify preparation for a death, being informed of a death and participating in rituals, as important elements of support for bereaved individuals with a learning disability (Dodd, McEvoy et al., 2005; Murray et al., 2000). An 'other' category was included in this question to cover responses relating to staff not recognising signs of grief, not acknowledging the relationship between the bereaved and the deceased and the level of dependency. These factors are considered to be contributors to the development of disenfranchised grief (Doka, 1989) and it is, therefore, concerning that only thirteen participants identified this category after training. A lot of information was covered within the one day training course and it could be argued that this did not allow for all areas to be covered in detail. Issues relating to supporting a bereaved individual with a learning disability

are considered to be particularly important and may, therefore, require greater attention during training.

These results show that, after training, staff possessed good levels of knowledge about factors related to having a learning disability that could create potential difficulties, grief reactions in individuals with learning disabilities and elements of support that could create further complications. There were, however, specific areas where knowledge did not improve significantly and alternative methods of improving staffs' understanding of these issues may need to be considered.

4.1.2.4 Knowledge of Supporting an Individual with a Learning Disability Through Bereavement.

The results showed that training significantly improved participants' knowledge about supporting an individual with a learning disability who has experienced bereavement, as measured by section three of the questionnaire. In relation to the final section of the questionnaire, no participant was able to identify all of the response categories for each question prior to training, suggesting that knowledge about supporting a bereaved individual with a learning disability was limited before training. This raises questions about the ability of staff to address the needs of their clients and offer appropriate and effective support to bereaved individuals with a learning disability.

The number of response categories identified within section three of the questionnaire increased after training. Previous research has stated that staff training

on bereavement should include information on proactive approaches to managing grief, which may improve the quality of support given to bereaved individuals with learning disabilities (Yanok & Beifus, 1993). In addition to this, encouragement to participate in bereavement rituals (Cathcart, 1991; James, 1995; Oswin, 1991) and recognising when specialist assistance is required (Blackman, 2003; Kitching, 1987) are considered to be important elements of effective support. After training, participants were more likely to identify 'proactive' and 'reactive' approaches, in relation to practical support that should be offered before and after bereavement. There were, however, only eleven participants that correctly identified the 'environmental' category post-training. This category covered issues including reducing multiple losses and maintaining continuity for bereaved individuals, including facilitating access to social support networks. These are considered to be important issues in relation to offering effective support at a time of bereavement (Crick, 1998; Doka, 1989; Kitching, 1987; McLoughlin, 1986; Oswin, 1991) and considerable time was allocated to these during the training course. Given the role of these issues in potentially creating greater difficulties for the bereaved individual, additional methods of improving staff knowledge of these factors may need to be identified.

While there was an increase in the response categories identified after training for indicators of complicated grief, less than half of the participants identified 'situational' and 'mental health' in their answers post training. No participants identified the 'verbal' category prior to training, which increased to sixteen after training. The most commonly identified response category both before and after

training was 'behavioural'. No previous research was found focusing on the knowledge of staff about recognising indicators of complicated grief. In regards to this study, a substantial amount of time was spent on clues to recognising complicated grief, with the use of a case example to promote understanding. While many participants identified themes that were discussed in relation to the case study, additional indicators of complicated grief were generally not identified. Recognising when specialist help is required is considered to be an important component of offering effective support to bereaved individuals with learning disabilities (Blackman, 2003; Kitching, 1987). Recognising complicated grief can be difficult, however, as indicators or symptoms can also be seen within the normal grieving process or in other disorders (Simos, 1979; Stroebe et al., 1993). To ensure referrals are made to appropriate services at the right times, it is perhaps necessary to consider further ways of supporting staff to recognise indicators of complicated grief and to distinguish between complicated grief and psychiatric disorders.

Despite none of the participants having received prior training specifically on bereavement and individuals with learning disabilities, prior to training over half of the participants were able to identify facilitation techniques that could be utilised to help an individual express their grief. After training, participants were more likely to identify the 'creativity' category, indicating increased knowledge of strategies that can be beneficial for bereaved individuals with additional communication difficulties. Participants' knowledge of communication methods that can be utilised to assist a bereaved individual with a learning disability to express their grief did not

generally improve after training, with only fourteen participants including a relevant response in their answers.

Given that research has stated that training alone may not be sufficient to change staffs' working practices in the longer term (Cullen, 2000; Ziarnik & Bernstein, 1982), it is perhaps necessary to consider further ways of improving the knowledge of staff about support strategies that may help them address the needs of a bereaved individual with a learning disability. It has been stated that adopting a lecture format and providing staff with verbal and/or written information, is generally ineffective for teaching staff about intervention techniques (Jahr, 1998). It could, therefore, be argued that training programmes need to incorporate more practical considerations, for example the use of role plays or observation, to enable staff to obtain greater knowledge of support strategies.

In summary, these results clearly show that a one day training course improved the knowledge of support staff about bereavement and grief, in general and in relation to individuals with learning disabilities. Training also significantly improved knowledge about supporting an individual with a learning disability who has experienced bereavement. There is a lack of previous research in this area to allow comparison of results and it is not possible to determine how this improved knowledge might impact on practice and the ability of staff to address the needs of their clients effectively. Exploration of the response categories identified before and after training also showed that fewer differences were found within section three of the questionnaire, which measured knowledge of supporting an individual with a

learning disability at a time of bereavement. Further research is, therefore, necessary to identify alternative methods of improving staff knowledge in this area.

4.1.3 Sustained Knowledge at Follow-up (Hypothesis 3)

The results showed a significant difference between knowledge prior to receiving training and at follow-up. Analysis of the data post-training to follow-up showed no significant differences in participants' knowledge in the three areas measured and overall scores, indicating that knowledge had been maintained over time. Hypothesis three was, therefore, upheld. There were no previous studies found that have assessed the impact of training on staff knowledge with the inclusion of a follow-up. There is, therefore, a lack of evidence from previous research to indicate the generalisability of these findings.

As mentioned previously, the results including the use of follow-up data should be interpreted with caution. The sample size was smaller at follow-up and this could be considered an influencing factor in this significant finding. A greater response rate would have enabled the researcher to identify whether knowledge gains were representative of the whole data set and likely to be maintained over a longer period of time.

In summary, participants' knowledge of bereavement and grief, in general and in relation to individuals with learning disabilities, and of supporting an individual with a learning disability at a time of bereavement, were maintained one month after

completion of the training course. These results, however, need to be interpreted with caution due to the reduced data available for follow-up analyses.

4.1.4 The Impact of Training on Confidence (Hypothesis 4)

The results showed training significantly improved participants' self rated levels of confidence about supporting an individual with a learning disability at a time of bereavement. The results showed that the group who received the training (group one) reported higher levels of confidence than those who had not yet received training (group two). Overall, self rated confidence levels were significantly higher immediately after training, compared to before training and this difference was maintained at a one month follow-up. Hypothesis four was, therefore, upheld.

The finding, which showed that training significantly improved participants' self rated confidence levels is consistent with previous research, which shows that training can improve staff confidence about offering support to individuals with learning disabilities when they have suffered bereavement (Reynolds et al., 2008). Participants' self rated confidence levels were also maintained at a one month follow-up. As mentioned previously, this result should be interpreted with caution due to the reduced sample size at follow-up.

The findings also showed that, in comparison with a control group, only the staff members who completed the training course showed a significant increase in self rated confidence levels. More importantly, there were no differences in self rated confidence levels between the two groups before training, as demonstrated by the

baseline measures. It could be argued that providing the participants with theoretical knowledge and practical guidance may have increased insight and skills, thereby resulting in an increase in reported confidence levels.

It is possible that additional factors impacted on the confidence levels of staff. On the front page of the questionnaire, all participants were asked to state any previous training they had received on bereavement and grief, whether they had access to bereavement guidelines within their organisation and if they had previous experience of providing support to an individual with a learning disability who had experienced bereavement. These questions were included in the questionnaire in order to obtain demographic and relevant background information on the participants. The impact of these factors on confidence levels were not assessed within the current study, but would benefit from further research. Previous research has shown that staff with more years of experience report higher confidence levels in relation to supporting an individual with a learning disability who has experienced bereavement (Murray et al., 2000). It is, therefore, possible that years of experience could have impacted on the self rated confidence levels of participants in the current study.

In addition to the above, it is important to acknowledge possible bias in participants' self rated confidence levels. The training, along with the distribution and collection of questionnaires, was conducted solely by the researcher. It is, therefore, possible that participants felt uncomfortable about reporting low levels of confidence after the training, given that the researcher had offered training specifically aimed at improving the knowledge and confidence of the attendees. On the basis of this, it is

not possible to rule out the impact of social desirability and acquiescence on the results obtained within the current study. As opposed to asking participants to rate their levels of confidence about supporting a bereaved individual with a learning disability pre and post training, an alternative method could have been utilised. As an example, participants could have been provided with case scenarios and asked to rate their level of confidence in offering support to each of the cases described.

In summary, the above results suggest that training significantly improved the self rated confidence levels of staff about supporting an individual with a learning disability who has experienced bereavement. The increased confidence levels were also maintained at a one month follow-up. There is, however, a need for further research to identify additional factors that may impact on the confidence levels of staff.

4.1.5 Summary

It is evident from the results that the knowledge of participants prior to receiving training was limited within the areas measured. The results of this study clearly demonstrate that participants' knowledge about bereavement and grief, in general and in relation to individuals with learning disabilities, and of offering support at a time of bereavement, improved significantly after training. This knowledge was also sustained over time, as evidenced by a one month follow-up. In addition to this, training significantly improved participants' self rated levels of confidence about supporting an individual with a learning disability who has experienced bereavement and these confidence levels were maintained one month after training. These results

demonstrate the benefits of a specialist training programme on bereavement for staff working with individuals with learning disabilities.

Exploration of the response categories within each question showed that there were also improvements in some specific areas of knowledge, demonstrating that training broadened participants' knowledge base. There is, however, a need to consider the scoring method used within the current study in relation to measuring the breadth and depth of knowledge, which will be discussed further in the next section.

4.2 METHODOLOGICAL CONSIDERATIONS

This section will highlight the methodological limitations of the study.

4.2.1 Study Design

When designing the study, one of the aims was to identify if receiving training improved knowledge compared with not receiving training. Two groups of participants were, therefore, required for the study, in order to identify the impact of receiving training and also to test the validity and reliability of the questionnaire. Prior to recruiting, it was considered that those who expressed interest in the study might be staff who had previous experience of supporting a bereaved individual with a learning disability or those who identified a need for bereavement training in order to increase their knowledge. There were, therefore, ethical concerns about recruiting a control group who did not receive any training. In order to address these concerns, it was decided to offer the training to a second group of participants a week later,

thereby allowing comparisons to be made while also ensuring all participants had the opportunity to attend the training course.

There were, however, implications with the study design. In order to highlight differences between those who received the training and those who did not and establish the test re-test reliability of the measure developed for use in the study, participants in group two were asked to complete the questionnaire on four occasions (one week before training, immediately before training, immediately after training and at a one month follow-up), whereas participants in group one completed the questionnaire on three occasions. Taking into account the effort required to complete the questionnaire, it is possible that participants in group two were less motivated to complete questionnaires on subsequent occasions. This may have also contributed to the poor response rate at follow-up.

4.2.2 Questionnaire Development

As an existing measure was not found to assess the knowledge of staff about bereavement and grief and more specifically in relation to bereavement in individuals with a learning disability, a questionnaire was developed for use in the study. Analysis of the questionnaire confirmed it to be a valid and reliable measure. The questionnaire was piloted with a population representative of participants recruited for the study and a group of professionals were asked to comment on the questionnaire, which established face, content and social validity. Inter-rater reliability scores were consistently good (see Table 8 and Appendix 10) and test re-test reliability scores were consistently high (see Table 10). The internal consistency

of the questionnaire was not assessed as the measure was designed to elicit a broad range of knowledge; therefore, it was not developed with the intention of producing scores that would correlate well with each other. The lack of an existing measure did not allow for construct validity and criterion related validity to be assessed. While the questionnaire conformed to a number of validity and reliability criteria, as outlined by Clark-Carter (2004), it is important to consider the use of a non-standardised questionnaire with limited psychometric properties in conducting research.

The test re-test reliability of the questionnaire was assessed using a time delay of one week between the completion of the questionnaires, of participants in group two, with no intervention in between. While some authors highlight the ideal time delay as a week (Nunnally & Bernstein, 1994), others recommend a gap of at least three months between data collection (Kline, 1993). Due to time constraints, the latter was not considered to be a feasible option.

There are well documented advantages and disadvantages of using a questionnaire based methodology in research (Burton, 1990; Robson, 2002; Sommer & Sommer, 2002). Advantages of using a questionnaire based research method include that they are considered to be economic and guarantee participants anonymity (Tao, 2003). There is, however, debate on the format of questionnaires and types of questions that should be utilised.

In order to strengthen the methodology of the study, an open question format was chosen to reduce response bias and allow for more detailed and accurate information to be gathered about staffs' knowledge (Vinten, 1995). The disadvantages of open questions are also recognised and their impact on the outcome of the current study is acknowledged. It could be argued that this question format requires greater effort from participants, which could potentially explain the low response rate at follow-up. There is also a risk of participants misinterpreting the questions. Within the current study, group one completed the first questionnaire with the researcher present and could, therefore, ask questions if any aspect of the questionnaire was unclear. This option was not, however, available to the participants in group two who completed the first questionnaire prior to attending the training course. The disadvantages of using open ended questions may have also been more significant post training, as participants may have been tired at the end of the day and eager to leave, therefore, decreasing the motivation to complete the questionnaire to the best of their ability. Regardless of the fact that significant differences were found between pre and post training knowledge, it is possible that greater differences could have been found if an alternative methodology had been used.

An additional consideration relates to the method used to score participants' answers on the questionnaire, which did not take into account the number of correct examples given within each response category. As a result of this, participants were awarded a score of one, whether they provided a single example or numerous examples of the same response category. The identified response categories were drawn from the literature and research base but the scoring system itself may not have sensitive

enough to ascertain the breadth and depth of knowledge held by the participants, which in turn could have impacted on the findings of the study.

The current study utilised a questionnaire composed of open ended questions. It is recognised that some of the questions were quite complex and utilised terms that many individuals may not be familiar with. There was, therefore, a risk that participants may misunderstand questions and provide incorrect responses. In addition to this, the questionnaire design did not take into account any difficulties with literacy that participants may present with. It is, therefore, possible that level of educational attainment may be a confounding variable that impacted on the outcome of the study. When conducting research a number of factors, including participants' characteristics, could impact on the observed outcome in a study. This can threaten the internal validity of the research as the observed effects could be due to a confounding variable as opposed to the independent variable (Clark-Carter, 2004). Gathering information on level of educational attainment would have allowed for this to be taken into consideration in the analysis, in order to avoid Type I errors.

The rationale for the methodology used within the current study has been highlighted within previous sections. The methodological limitations of the questionnaire have also been discussed and it is acknowledged that an alternative methodology could have been utilised within the current study. A questionnaires that uses a yes/no or multiple choice format could have been developed, which may require less effort and time to complete (Gillham, 2000). It has also been stated that such methods can reduce the risk of questions being misunderstood and may pose fewer difficulties for

less articulate individuals to complete (Leung, 2001). On the other hand, the researcher could have adopted a qualitative approach to gain information on the knowledge and confidence of staff prior to and after training. Data collection utilising a qualitative based research methodology could include the use of focus groups or in depth interviews (Robson, 2002). It could be argued that this method would allow for richer and more detailed information to be gathered about participants' knowledge, attitudes and beliefs, which may fail to be captured solely through the use of a questionnaire. This method would also allow the researcher to clarify questions, thereby reducing the risk of misinterpretation and incorrect responses. There are, however, limitations with qualitative research. Data collection utilising this method is generally very labour intensive, resulting in a smaller number of participants being included in the research (Gillham, 2000). In addition to this, there are criticisms relating to researcher bias and the lack of reproducibility and generalisability of findings (Robson, 2002).

It has been suggested that, in isolation, training is not sufficient to change the working practices of staff in the longer term (Cullen, 2000; Ziarnik & Bernstein, 1982) and that discrepancies often exist between the information provided by staff and what they actually do in practice (Hastings & Remington, 1994). It could, therefore, be argued that while staff knowledge of each of the areas assessed may have been obtained effectively in the study, it may not necessarily reflect, or impact on, practice.

As mentioned previously, descriptive information was gathered on participants' years of experience working with individuals with learning disabilities, previous training on bereavement and experience of supporting bereaved individuals with a learning disability. A limitation of the current study was that this information was not included in the analysis to identify any relationships between these factors and knowledge and confidence levels of staff members. In addition to this, it has been stated that staff/carers with no experience of bereavement, personally or professionally, may lack knowledge about grief and feel inadequate in offering support at such times (Lake, 1984; Simos, 1979). It has been stated that prior experience of bereavement, either personally or professionally, can allow individuals to draw on experience when offering support to others (Goodall et al., 1994). It would, therefore, have been useful within the current study to gather information from participants regarding their personal experience of bereavement and more detailed information on their previous experience of supporting bereaved individuals with learning disabilities. While it is acknowledged that some individuals may be reluctant to comment on their personal experiences of bereavement, these factors would be a useful inclusion within the analyses to identify any relationships between prior experience and reported levels of knowledge and confidence.

4.2.3 Staff Training

The literature and research within the area of bereavement and learning disability highlights the need for staff training to improve knowledge and subsequently enhance the support offered to individuals with learning disabilities who have suffered bereavement (Cochrane, 1995; Harper & Wadsworth, 1993; Hollins &

Sinason, 2000; Kitching, 1987; MacHale & Carey, 2002; McEvoy & Smith, 2005; Oswin, 1985). In spite of this, there is a lack of specialist training programmes on bereavement for staff working with individuals with learning disabilities (Crick, 1988; Neuberger, 1987; Oswin, 1992). As a result of this, a training programme was required to be developed specifically for use in the study. The training programme used was developed for support staff based on the literature and research currently available about bereavement and grief, in general and in relation to individuals with learning disabilities and of support strategies.

As mentioned earlier, the methodology used for the questionnaire required effort on the part of the participants to complete, therefore, additional evaluation of the training course was not conducted. In hindsight, this would have been a useful tool to allow participants to comment on the relevance of the training course and its applicability to their daily practice. While participants were given the option at the end of the questionnaire to make any additional comments about the training course, specifically regarding its usefulness, relevance and applicability, only five participants provided written comments. The comments given stated that the content and presentation of the training course was very good and that information would be fed back to other colleagues within their organisation. Verbal feedback was, however, received from a considerable number of the participants who described the training as informative and useful.

While the training course and questionnaire were designed with consideration of the literature and evidence base within the area studied, it has been argued that training

programmes that reflect the needs identified by staff members are more effective (Kauffman, 1994). It could, therefore, be argued that conducting a preliminary needs assessment and developing a training course based on identified needs, could potentially be more relevant to staff and produce greater outcomes.

4.2.4 Sample Size

The initial number of participants recruited for the study was seventy; however, due to staff sickness absence and other staff members consequently being required to cover shifts, twenty two individuals had to withdraw from the study. The final sample size was sufficient for statistical power (Clark-Carter, 2004) and supported analysis of the data pre and post-training. The reduced response rate at follow-up (15/48 questionnaires were returned), however, had implications for achieving statistical power in the analysis (Clark-Carter, 2004). As a result, a significant amount of data was not used in the analyses that compared pre and post-training with follow-up data. Consideration should, therefore, be given to the impact that this had on the results.

While it is not uncommon for follow-up procedures to yield low response rates, in the current study, only one questionnaire was initially returned from the forty eight sent out. In order to ensure a maximum response rate, a great deal of time and effort was spent contacting individual participants and service managers, asking that they remind staff to complete the follow-up questionnaires. Due to time constraints, it was not possible to pursue this further, which may have had implications for the final response rate.

4.2.5 Time Constraints

If there had been more time available, it would have been possible to send further reminders to participants in order to increase the response rate. When designing the study, it was decided to conduct a one month follow-up to identify if knowledge gains would be sustained after a period of time had elapsed following the training course. Due to time constraints, it was not possible to consider a longer term follow-up in order to ascertain if gains would be maintained over a greater period of time.

4.2.6 Generalising the Findings of the Study

The generalisability of the findings of this study, to staff in other geographical areas or organisational settings, is difficult to ascertain. Participants were recruited from service provider organisations that offer support to individuals with learning disabilities. It would be interesting to ascertain if similar findings would be found in family carers who offer support to relatives with a learning disability or professionals working within specialist learning disability services. Unfortunately, no similar research is available on the knowledge of family carers and no prior research was found specifically on the impact of training on the knowledge of support staff. Previous research, however, does suggest that good levels of knowledge exist in staff working in health and social care settings (Murray et al., 2000) and across different geographical areas (Dodd, McEvoy et al. 2005).

4.3 ETHICAL AND CLINICAL IMPLICATIONS

The main aim of the current study was to assess the impact of a one day training course on bereavement and grief, on the knowledge and confidence levels of support staff who currently work with individuals with learning disabilities. Training was found to have a significant impact on knowledge and confidence, supporting previous research that staff training can increase knowledge (McKenzie et al., 2000; McKenzie et al., 2002) and confidence (Reynolds et al., 2008).

It is still not known the degree to which training will actually impact on staffs' practice and so, while staff may have greater awareness and insight into the issues surrounding bereavement and grief in this client group, they may require more practical assistance and ongoing support to ensure the needs of their clients are met. Research has stated that a substantial number of staff who provide support to individuals with learning disabilities have not received training to enable them to meet the need of their clients (McVilly, 1997; Smith et al., 1996). This raises concerns about the ability of staff to meet the demands of their job and be adequately prepared for their role. Bereavement and grief are recognised as taboo subjects, which individuals prefer to avoid than deal with (Brelstaff, 1984; Conboy-Hill, 1992; Kitching, 1987), but due to the potential difficulties and additional vulnerabilities for individuals with learning disabilities, it is vitally important that staff are aware of such issues and have the skills to adequately meet the needs of their clients at a time of bereavement.

The findings of the current study clearly demonstrated that training improved the knowledge and confidence of staff and, therefore, it is important to consider the implications for staff who have not received such training. Staff providing support to individuals with a learning disability have a duty of care to ensure that appropriate action is taken to prevent their clients being exposed to risk or harmful situations (Read & Elliott, 2003). Limited knowledge of the areas assessed, prior to training, raises concerns that staff may not possess the necessary skills to identify grief responses and complications in their clients, which may impact on the support offered at a time of bereavement. Individuals with learning disabilities are now more likely to live within community settings, thereby increasing the demand on carers and support staff to ensure client's needs are addressed and appropriate support is given (Caine et al., 1998; Scottish Executive, 2000). There are ethical concerns about individuals with learning disabilities receiving support from staff members who have limited knowledge and skills to support them through bereavement. It could be argued that bereavement training should be included within the mandatory training packages offered to all staff within support provider organisations.

A lack of knowledge in support staff could potentially result in bereaved individuals with learning disabilities being inappropriately referred to specialist services due to the inability of staff to recognise grief or offer effective support. One of the contributing factors to the researcher undertaking this study was due to a number of referrals received within the learning disability service highlighting, for example challenging behaviour as the presenting difficulty, which after assessment was concluded to be related to bereavement. Within these referrals, bereavements had

often occurred years previously and presentations were not considered related to be grief related due to the time that had elapsed. If training on bereavement was more widely available for staff, grief reactions could be recognised and facilitated, with referral to specialist services being reserved for those individuals suffering considerable difficulties or complicated grief reactions requiring therapeutic intervention.

4.4 FUTURE RESEARCH

Despite the methodological limitations of the study, the findings highlight a number of areas deserving of further research, some of which have been mentioned in previous sections. This section will discuss areas for future research.

Bereavement and grief in individuals with a learning disability is an area of limited research. In particular, limited research has been conducted on the impact of training on knowledge and confidence of staff, which could potentially impact on practice. This clearly advocates the need for further research similar to that undertaken in this study. In the current study, the main aim was to analyse the impact of staff training on knowledge and confidence levels. It would, however, have been useful to also consider any significant relationships between years of experience, prior training on bereavement and access to guidelines on bereavement, on staff members knowledge and confidence. While participants were asked to provide such information in the questionnaire, these factors were not included in the analysis of the data.

The research findings suggest that knowledge levels of staff, within the three areas measured, were relatively low prior to receiving training. Research has demonstrated that individuals with learning disabilities may be more vulnerable to developing complications in the grieving process (Bonell-Pascual et al., 1999, Emerson, 1977) and that support offered at a time of bereavement may be insufficient to meet the needs of the client (Murray et al., 2000). It is, therefore, important that staff who provide support to individuals with learning disabilities are aware of these issues and have sufficient knowledge to enable them to respond appropriately at such times. It has also been stated that training alone may not lead to changes in practice (Cullen, 2000; Ziarnik & Bernstein, 1982) and that knowledge does not always reflect practice (Hastings & Remington, 1994). Future research should, therefore, consider the use of additional methods of providing staff with the skills to support a bereaved individual with a learning disability. Methods of improving practice could include offering ongoing practical support, for example observation of staff-client interactions, supervision, role play, use of video materials or workbooks and assisting in the development of bereavement guidelines. Alternative methods of improving the knowledge and skills of staff may also be less time consuming than attending a training course and future research would determine if these were as effective, or produced greater outcomes on knowledge and skills compared to training alone.

The participants recruited for the current study all worked within support provider organisations in the researcher's health board area. It has been stated that approximately sixty per cent of individuals with learning disabilities live at home and

are cared for by their families (Department of Health, 2001), therefore, there may also be a need for family carers to be aware of bereavement related issues. This would not only enhance their knowledge, but may also allow for future care plans to be developed, which could potentially reduce the likelihood of the individual with a learning disability experiencing multiple losses after bereavement.

Previous research has also highlighted that individuals with learning disabilities can benefit from being provided with information about death and dying (Luchterhand & Murphy, 1998; Yanok & Beifus, 1993). In order to adopt a more proactive approach it may, therefore, be useful to consider the role of education groups specifically designed for individuals with learning disabilities to teach them about death and grief.

Resource packs are a useful means of ensuring information is readily available to staff providing support to individuals with a learning disability. Resource packs have been developed for staff based on specific areas, for example dementia (Dodd et al., 2003) and autistic spectrum disorder (Broderick & Mason-Williams, 2008). Future research could aim to develop a resource pack focusing on bereavement in individuals with learning disabilities. This would allow easy access to the key issues relevant to this client group, provide information on support strategies and help promote consistency of approach.

4.5 CONCLUSIONS

The aim of this thesis was to investigate the impact that a one day training course had on staffs' knowledge about bereavement and grief, in general and in relation to individuals with a learning disability, and of supporting an individual with a learning disability at a time of bereavement. This study also aimed to investigate the impact of training on staff's self rated levels of confidence about supporting an individual with a learning disability who has experienced bereavement. The findings of the study demonstrated significant improvement in knowledge across the three areas and a significant increase in self rated confidence levels after training. Both knowledge and confidence levels were maintained at a one month follow-up. In addition, training significantly changed the type of knowledge held by staff, indicating that training broadened their knowledge of the three areas measured.

Unfortunately, bereavement and learning disability is an area of limited research. There is a lack of standardised measures available to assess the knowledge of staff who work with individuals with learning disabilities. In addition to this, there is a lack of training packages focusing specifically on bereavement and learning disability. The researcher was, therefore, required to develop a questionnaire and training course specifically for use within the current study. The questionnaire was demonstrated to be reliable and valid and the significant improvements in knowledge and confidence levels of staff support the benefits of the training course.

This was considered to be an important area of research as staff have a duty of care to ensure the individuals with learning disabilities that they support are protected

from harm and receive appropriate support. Staff, therefore, need to be aware of bereavement issues in this client group, including recognising signs of grief and potential difficulties that may occur, along with possessing adequate knowledge of appropriate support strategies.

While taking into account the methodological considerations of the study, it would appear that prior to training staff held low levels of knowledge about bereavement and grief, in general and in relation to individuals with learning disabilities, and of support that can be offered at a time of bereavement. It is, therefore, possible to conclude that staff were not adequately equipped with the knowledge and skills to offer effective and appropriate support to their clients at a time of bereavement. Further research needs to consider how to address gaps in understanding and enhance staff knowledge to ensure individuals with learning disabilities are not disadvantaged or neglected at a time of bereavement.

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APPENDICES

7.1 APPENDIX 1: Letter Stating Full Ethical Application Not Necessary

NHS

Local Research Ethics Committee

Telephone:
Facsimile:

28th August 2007

Trainee Clinical Psychologist

Dear

ETHICAL REVIEW

Thank you for seeking the Committee's advice about the project sent to me by e-mail.

The Chairman has advised that the project is not one that is required to be ethically reviewed under the terms of the Governance Arrangements for Research Ethics Committees in the UK.

Yours sincerely

pp

SECRETARY TO THE GROUP

7.2 APPENDIX 2: Consent Form for Participation in the Study

Bereavement and Learning Disability Study

Dear member of staff,

I am a Trainee Clinical Psychologist at the University of Edinburgh. I currently work for NHS within the learning disability service. As part of my doctorate I am required to complete a thesis. I have chosen to research 'bereavement in individuals with a learning disability' and would be very grateful for your help. In particular I am interested in the knowledge of staff members about bereavement and grief, bereavement and grief in individuals with learning disabilities and supporting an individual with a learning disability through bereavement. I will be offering a free training course in order to provide you with information on bereavement and more specifically, on the grieving process in individuals with learning disabilities. To take part in this research, you will need to complete the attached questionnaire.

The questions are for research purposes only and all answers will be completely confidential. No individuals will be identified and no one except the researcher will see the completed questionnaires. I will be asking each individual to place the last four digits of their telephone number at the top of the questionnaire. This is solely for the purposes of matching up the before, after and follow-up questionnaires and will not be used for any other means. If there are any questions that you would prefer not to answer, it would be much appreciated if you could indicate this on the questionnaire as opposed to leaving a blank response. Please answer all questions as honestly as you can.

If you would like to take part in this research, please fill in the consent form below and then complete the attached questionnaire.

I agree to take part in this study.

Name: _____

Thank you very much

7.3 APPENDIX 3: Letter to Service Managers Outlining the Study and Request for Participants

Dear (name of service manager),

I am a Trainee Clinical Psychologist at the University of Edinburgh and I currently work for NHS within the Learning Disability Service. As part of my doctorate I am required to complete a research project. I have a special interest in working with adults with learning disabilities and have, therefore, decided to complete my research in this area. The topic of my research is 'Bereavement in Individuals with a Learning Disability' and I am writing to ask whether any of the staff members within your organisation would be interested in taking part in the study.

My research aims to investigate the impact of staff training on knowledge about bereavement and grief, bereavement and grief in individuals with a learning disability and supporting an individual with a learning disability at a time of bereavement. I am also interested in whether training improves the confidence levels of staff with regards to offering support to an individual with a learning disability who has suffered bereavement. I am, therefore, looking to recruit staff members who currently provide regular support to individuals with a learning disability and who are interested in learning more about bereavement and grief.

If any of your staff would be interested in participating, the following is a summary of what would be involved. Staff members would be randomly allocated to one of two groups and I will be asking staff to fill out a questionnaire, which has been designed to gather information on their current knowledge about bereavement and grief. In order to evaluate the impact of training on knowledge, I will be asking staff who are allocated to group one to complete the questionnaire immediately before receiving the training. Those staff members that are allocated to group two will be asked to complete the questionnaire twice before attending the training course, a

week before the training is scheduled to take place and again immediately before receiving the training. This is for the purpose of identifying whether the questionnaire is useful tool to evaluate staff knowledge in relation to the areas mentioned above. I will be offering a free training course which will provide information on bereavement and grief, in general and also in relation to individuals with a learning disability and regarding support that can be offered at a time of bereavement. In order to evaluate the impact of the training on knowledge I would ask staff to complete the same questionnaire at the end of the training day and also again approximately a month after the training course. The questionnaire should take approximately 10 minutes to complete.

If there are any staff members within your organisation who would be interested in taking part in the study, please provide them with the information contained in this letter. If you have any questions about the research or wish to discuss it further, please contact me at the number above or by e-mail.

I very much appreciate you taking the time to read this letter and I look forward to hearing from you.

Yours sincerely

Trainee Clinical Psychologist Chartered Clinical Psychologist

7.4 APPENDIX 4: Covering Letter for Follow-up Questionnaires (sent via e-mail)

Dear (name of participant),

Thank you again for taking part in my research project and attending the training course on . You may recall that on the day of the training course, the questionnaire was filled out before and after the training event. I am writing to ask if you spare 10 minutes to complete the questionnaire one final time. This will allow me to identify if any benefits of the receiving the training course have been maintained after a certain period of time has passed.

I have attached the questionnaire. It would be appreciated if you could complete it and return it to me as soon as possible. The questionnaire can be e-mailed back to me or sent by post if you would prefer. I would like to remind you that all questionnaires are anonymous and confidential. Those sent by e-mail will be printed out and the e-mail deleted immediately.

This is the final time I will be asking you to complete the questionnaire and will be the end of your involvement in the research. Thank you again for your participation.

Yours sincerely

Trainee Clinical Psychologist Chartered Clinical Psychologist

7.5 APPENDIX 5: Questionnaire

Thank you for agreeing to take part in this study.

1. Please fill in the information below before completing the questionnaire.
2. The questionnaire is anonymous and the information you provide will not be shared with anyone else. The first section requests that you enter the last 4 digits of your telephone number. This is to allow questionnaires completed before and after the training course to be matched.
3. Once you have completed the questionnaire please hand it to the researcher or return it via e-mail or post.

Please let me know if you have any questions.

Last four digits of your telephone number: _____

Age: _____

Gender: _____

What is your occupation within the organisation you currently work for? _____

For how many years have you worked with people with learning disabilities? _____

Instructions: For each of the following questions please circle the appropriate response.

1. Have you ever worked with someone with a learning disability going through bereavement?

Yes No Don't know

2. Do you have access to bereavement guidelines within your organisation?

Yes No Don't know

3.a Have you ever received training on bereavement for people with learning disabilities?

Yes No

3.b If the answer to the above question is 'Yes' please give details of the training you have received.

4. How confident do you feel about supporting someone with a learning disability who has experienced bereavement? (Please indicate with a cross on the scale that represents your view)

|_____|

No Confidence Totally Confident

Please now complete the attached questionnaire

Bereavement and Grief

Instructions: The following are general questions about bereavement. Please read each question carefully and write your answers in the space provided.

1. What are the 'tasks of grieving'?

2. Please can you describe some of the grieving responses often associated with 'normal grieving'?

3. What is your understanding of the term 'complicated grief'?

4. What factors can influence a person's response and reaction to bereavement?

Bereavement, Grief and Individuals with Learning Disabilities

Instructions: The following questions are specifically about bereavement and people with learning disabilities. Please read each question carefully and write your answers in the space provided.

1. What is it about having a learning disability that can make grief more difficult?

2. Aside from the responses to grief recognised within the general population, how else might grief be displayed in someone with a learning disability?

3. When offering support at a time of bereavement, what things can increase the likelihood of someone with a learning disability developing a complicated grief reaction?

Supporting an Individual with a Learning Disability Through Bereavement

Instructions: The following questions are about supporting an individual with a learning disability through bereavement. Please read each question carefully and write your answers in the space provided

1. What practical support can you offer to assist someone with a learning disability before and after a death?

2. What are some of the clues that someone might be suffering a 'complicated grief reaction'?

3. When providing emotional support to someone with a learning disability, what techniques/skills can you use to help them express their grief?

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE

7.6 APPENDIX 6: Response Categories for Individual Questions in Section One of the Questionnaire

Section 1: Bereavement and Grief

Table 2: Response Categories for Bereavement and Grief Questions

QUESTION	RESPONSE CATEGORY	DESCRIPTION	EXAMPLES
Question 1: What are the 'tasks of grieving'?	Acceptance	An accurate example of the main components of task 1	Accepting the reality of the loss Accepting the person is dead and won't return
	Experience	An accurate example of the main components of task 2	To experience the pain of grief Common responses include emotional, behavioural and physiological reactions
	Adjustment	An accurate example of the main components of task 3	To adjust to an environment without the deceased Developing skills to fulfil roles previously completed by the deceased
	Resolution	An accurate example of the main components of task 4	To find a place for the deceased in one's life and move on. Being able to form new relationships
Question 3: What is your understanding of the term 'complicated grief'?	Duration	Any reference to the length of the grieving process	Grief that is absent or prolonged No apparent progression through process Remaining in state of grief
	Intensity	Any reference to the nature of the grief response	Symptoms may be more intense and overwhelming Individual may be unable to cope
	Subtype	Any reference to types of complicated grief reaction	Chronic, delayed, masked, exaggerated, absent, inhibited

Table 2 continued: Response Categories for Bereavement and Grief Questions

QUESTION	RESPONSE CATEGORY	DESCRIPTION	EXAMPLES
Question 4: What factors can influence a person's response and reaction to bereavement?	Intrapersonal	An accurate example of factors related to the individual	Previous loss experiences and how these were grieved Mental health history Coping style Beliefs and values
	Interpersonal	An accurate example of factors related to interactions between individuals	Available social support Relationship to the deceased Strength and nature of attachment/levels of dependency
	Circumstances of Death	Any reference to mode of death or subsequent impact on the individual	Nature of the death (natural, accidental, suicidal, homicidal) Sudden death or anticipated Levels of disruption after a death

7.7 APPENDIX 7: Response Categories for Individual Questions in Section Two of the Questionnaire

Section 2: Bereavement, Grief and Individuals with Learning Disabilities

Table 4: Response Categories for Bereavement, Grief and Learning Disability Questions

QUESTION	RESPONSE CATEGORY	DESCRIPTION	EXAMPLES
Question 5: What is it about having a learning disability that can make grief more difficult?	Communication	Any reference to difficulties with communication that could hinder the expression of grief	Limited communication could mean the individual cannot express feelings verbally Could lead to frustration/isolation Distress may be apparent through changes in behaviour or mood
	Intellectual Ability	Any reference to reduced intellectual ability related to concept of death	Concept of death is related to level of cognitive ability, age and life experiences Level of understanding of the concept of death and of ageing process/life cycle Full understanding of the meaning of death is not necessary to feel a loss
	Comorbidity	Any reference to other diagnoses that could further complicate grief	Sensory impairments Other diagnoses, e.g. autistic spectrum disorder, dementia

7.7 APPENDIX 7 CONT: Response Categories for Individual Questions In Section Two of the Questionnaire

Section 2: Bereavement, Grief and Individuals with Learning Disabilities

Table 4 continued: Response Categories for Bereavement, Grief and Learning Disability Questions

QUESTION	RESPONSE CATEGORY	DESCRIPTION	EXAMPLES
Question 7: When offering support at a time of bereavement, what things can increase the likelihood of someone with a learning disability developing a complicated grief reaction?	Unpreparedness	Any reference to lack of preparation for a loss	Not being informed of a death Not given the opportunity to prepare for a death Lack of preparation could lead to multiple losses
	Exclusion	Any reference to lack of participation in rituals	Not encouraged to/excluded from participating in rituals, for example viewing the body, attending the funeral
	Isolation	Any reference to lack of social support	Restricted or absent social support network Withdrawal or denial of support by others
	Other	Any reference to additional features of support that could complicate the grieving process	Staff not recognising signs of grief Staff not acknowledging relationship between bereaved and deceased Nature of relationship with deceased and level of dependency

7.8 APPENDIX 8: Response Categories for Individual Questions in Section Three of the Questionnaire

Section 3: Supporting an Individual with a Learning Disability Through Bereavement

Table 6: Response Categories for Questions Related to Supporting an Individual with a Learning Disability Through Bereavement

QUESTION	RESPONSE CATEGORY	DESCRIPTION	EXAMPLES
Question 8: What practical support can you offer to assist someone with a learning disability before and after a death?	Proactive	Any reference to preparation for a loss	Visiting relatives who are ill Teach about death and dying through use of natural opportunities
	Reactive	Any reference to support offered after a death	Breaking the news of a death, not withholding information but being honest and explaining a death in a way the person will understand Encourage involvement in rituals Recognise when specialist help is required
	Environmental	Any reference to minimising change following a death	Maintaining continuity of lifestyle Not moving the individual straight away, avoiding frequent staff changes, facilitating access to social support networks

7.8 APPENDIX 8 CONT: Response Categories for Individual Question in Section Three of the Questionnaire

Section 3: Supporting an Individual with a Learning Disability Through Bereavement

Table 6 continued: Response Categories for Questions Related to Supporting an Individual with a Learning Disability Through Bereavement

QUESTION	RESPONSE CATEGORY	DESCRIPTION	EXAMPLES
Question 10: When providing emotional support to someone with a learning disability, what techniques/skills can you use to help them express their grief?	Facilitation	An accurate example of skills to facilitate the expression of grief	Active listening, empathy, openness, honesty, sincerity Allowing time and space to grieve Normalising reactions
	Communication	An accurate example of communication techniques to help an individual express their grief	Provide opportunities to talk about feelings Use terms the person will understand Avoid euphemisms Answer questions honestly and allow repetition
	Creativity	An accurate example of creative strategies that can be used to facilitate grief	To retain memories of the deceased by creating memory boxes, life story books Use artwork, story books, photos Useful for those with communication difficulties

7.9 APPENDIX 9: Exploratory Analysis of Data

Table7: Skewness and Kurtosis Values of the Variables Used in Analysis

VARIABLE	SKEWNESS VALUE	STANDARD ERROR OF SKEWNESS	KURTOSIS VALUE	STANDARD ERROR OF KURTOSIS
Confidence pre-training	-0.190	0.343	-0.916	0.674
Confidence post-training	-0.706	0.343	-0.433	0.674
Confidence follow-up	-0.778	-0.778	-0.055	1.121
Section 1 of Questionnaire pre-training	0.814	0.343	0.756	0.674
Section 1 of questionnaire post-training	-0.535	0.343	-0.435	0.674
Section 1 of questionnaire follow-up	0.193	0.580	-1.044	1.121
Section 2 of questionnaire pre-training	0.601	0.343	-0.543	0.674
Section 2 of questionnaire post-training	0.910	0.343	0.641	0.674
Section 2 of questionnaire follow-up	0.312	0.580	0.732	1.121
Section 3 of questionnaire pre-training	0.551	0.343	0.218	0.674
Section 3 of questionnaire post-training	0.132	0.343	-0.463	0.674
Section 3 of questionnaire follow-up	0.200	0.580	-1.490	1.121
Total score pre-training	0.718	0.343	0.349	0.674
Total score post-training	0.046	0.343	-0.481	0.674
Total score follow-up	0.076	0.580	-1.125	1.121

7.10 APPENDIX 10: Inter-Rater Levels of Agreement and Kappa Scores for Individual Response Categories Within each Question

Table 9: Inter-Rater Levels of Agreement and Kappa Scores for Individual Response Categories

QUESTION NUMBER	QUESTION	FACTOR	KAPPA VALUE	LEVELS OF AGREEMENT ACCORDING TO FLEISS (1981)
1	What are the 'tasks of grieving'?	Acceptance	1.00	Excellent
		Experience	1.00	Excellent
		Adjustment	1.00	Excellent
		Resolution	1.00	Excellent
2	Please can you describe some of the grieving responses often associated with 'normal grieving'?	Physiological	1.00	Excellent
		Emotional	1.00	Excellent
		Behavioural	1.00	Excellent
		Cognitive	0.92	Excellent
3	What is your understanding of the term 'complicated grief'?	Duration	0.75	Excellent
		Intensity	0.75	Excellent
		Subtype	0.88	Excellent
4	What factors can influence a person's response and reaction to bereavement?	Intrapersonal	1.00	Excellent
		Interpersonal	0.92	Excellent
		Circumstances of Death	1.00	Excellent
5	What is it about having a learning disability that can make grief more difficult?	Communication	0.84	Excellent
		Intellectual Ability	1.00	Excellent
		Comorbidity	1.00	Excellent
6	Aside from the responses to grief recognised within the general population, how else might grief be displayed in someone with a learning disability?	Behavioural	1.00	Excellent
		Mental Health	1.0	Excellent
		Non Verbal	0.65	Good

7.10 APPENDIX 10 CONT: Inter-Rater Levels of Agreement and Kappa Scores for Individual Response Categories Within each Question

Table 9 continued: Inter-Rater Levels of Agreement and Kappa Scores for Individual Response Categories

QUESTION NUMBER	QUESTION	FACTOR	KAPPA VALUE	LEVELS OF AGREEMENT ACCORDING TO FLEISS (1981)
7	When offering support at a time of bereavement, what things can increase the likelihood of someone with a learning disability developing a complicated grief reaction?	Unpreparedness	0.91	Excellent
		Exclusion	1.0	Excellent
		Isolation	0.78	Excellent
		Other	1.00	Excellent
8	What practical support can you offer to assist someone with a learning disability before and after a death?	Proactive	1.00	Excellent
		Reactive	1.00	Excellent
		Environmental	1.00	Excellent
9	What are some of the clues that someone might be suffering a 'complicated grief reaction'?	Situational	1.00	Excellent
		Behavioural	0.84	Excellent
		Mental health	1.00	Excellent
		Verbal	1.00	Excellent
10	When providing emotional support to someone with a learning disability, what techniques/skills can you use to help them express their grief?	Facilitation	1.00	Excellent
		Communication	1.00	Excellent
		Creativity	1.00	Excellent